ASSISTED HUMAN REPRODUCTION

NAVIGATING OUR FUTURE

Report of the Ministerial Committee
on Assisted Reproductive Technologies
July 1994

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ASSISTED HUMAN REPRODUCTION

NAVIGATING OUR FUTURE

Members of the Committee

Mr Bill Atkin - Reader in Law -Victoria University
Dr Paparangi Reid - Health Researcher - Wellington School of Medicine

Hon Douglas Graham
Minister of Justice
Parliament Buildings
WELLINGTON

Dear Mr Graham

We were appointed in April 1993 to the two person Committee on Assisted Reproductive Technologies to study and report on assisted reproductive technologies.

We were required to submit our Report to you by 30 April 1994 but the time was later extended to 31 July 1994.

We have pleasure in submitting our Report as requested.

W R Atkin

M J P Reid

Wellington
29 July 1994

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ACKNOWLEDGEMENTS

We wish to record our thanks to many people who assisted in the preparation of this report. First, we acknowledge all the people who wrote to us and spoke with us. Some of them sharing very private and personal stories. We received submissions of high quality, very carefully prepared and well thought through. We spoke to individuals and groups in both formal settings and casually. More than once, the passing conversation or brief comment has helped ideas to gel for us.

We also thank the officials whose help and support were essential for the completion of our task. In particular, we appreciated the assistance of Mr Bruce Slane, the Privacy Commissioner and his team, and Mrs Margaret Mulgan along with the staff of the Human Rights Commission. Members of the Department of Justice and the Ministry of Health were more than willing to put themselves out for us, but above all we record our appreciation to our administrative back-up staff from Tribunals Division of the Justice Department, Robert Wesney, Sandra Prichard and Debbie Radford. Their organisational efficiency eased our task enormously, and especially as the completion of the report approached, their endurance and patience were extraordinary. They navigated us wonderfully well through calm seas and rough ones.

We thank Lorna Dyall and Lady Keith for being willing to prepare the excellent analysis of the submissions, which is appended to the report. Our appreciation also goes to our colleagues and students, who may have sometimes wondered what we were up to. The secretarial efforts of Christine Ross and Carol Sorenson, in particular, were of great assistance.

Finally, we mention our partners and families. They put up with our absences, our unavailability and our lack of attention. Amazingly, we have all held together!

Tena koutou katoa.

MINISTERIAL COMMITTEE ON ASSISTED REPRODUCTIVE TECHNOLOGIES

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EXECUTIVE SUMMARY

Assisted human reproduction is an area of acute public interest. Technology has been inclined to outstrip our common ethical understandings and legal framework. The State has a proper protective role to ensure that all parties are protected, so that we can all journey safely into the future.

This report reviews practice within New Zealand and we find that accredited providers of reproductive services have been acting in a responsible manner, and have been proactive in developing new policies, such as openness with respect to donors of gametes. Accreditation of providers by the Australian Reproductive Technologies Accreditation Committee (RTAC) has been a significant development working to this country's advantage.

The report gives a general sweep of overseas trends in new technology and legal regulation. We consider that there are good reasons for New Zealand to work out its own responses to the new developments.

In order to craft the right policies for New Zealand, the report sets out the guiding principles we used to assess various options. We see these as navigation points for the voyage ahead.

The State must have a system in which the public can have confidence. Given the mobile state of knowledge and scientific discovery, it is essential that we have transparent yet flexible structures in place. There are many good aspects of the present system, including the roles of RTAC, professional bodies, ethics committees and agencies such as the Privacy Commissioner and the Human Rights Commission. Our preferred options build on the best points of the foundation which already exists.

Our principal recommendation is that a new advisory and overseeing body be established, to be called the Council on Assisted Human Reproduction. We consider that a separate New Zealand licensing system is not necessary but there is a call for a public body which can be the focus for the Government and the community on matters relating to assisted reproduction. Its functions would include, among other things, the preparation of codes of practice and guidelines to assist providers, consumers and the general public.

We also recommend the tightening of professional control over health professionals and any others who may wish to operate in the assisted reproduction area. Our aim is to ensure that only accredited health agencies offer such services. It would thus become an offence to run an assisted reproduction business without accreditation.

One of our guiding principles is the right to know genetic origins. In considering the question of access to genetic and birth information where there has been donation of gametes or embryos, we found the great weight of submissions and oral expressions of opinion favoured a policy of openness rather than secrecy. In our view, the appropriate mechanism for giving effect to this policy is a code issued under the Privacy Act, and we recommend that the Government ask the Privacy Commissioner to act accordingly and to be given appropriate funding.

The Human Rights Act has forced a reconsideration of who is entitled to use the services of assisted reproduction providers. While we believe that more public debate is justified, we are of the view that some of the issues of concern to people can be addressed within the existing framework of the Act. The Act also highlights the question of who is entitled to publicly provided services. This needs to be addressed by those considering core health and disability services.

There is a spectrum of activities which go under the label of surrogacy, and there is a wide range of views about different kinds of surrogacy. Apart from the proposed changes to the Medical Practitioners Act, no criminal offences in relation to surrogacy should be created. Policy in this area should discourage underground activity and the need to resort to overseas agencies. Appropriate record keeping, the freedom to continue cultural practices such as whangai and the right to know genetic origins must influence the development of policy in relation to surrogacy.

CHAPTER 1

TERMS OF REFERENCE

AND ESTABLISHMENT OF MCART

INTRODUCTION

In 1993, the Minister of Justice announced the formation of a two person Ministerial Committee on Assisted Reproductive Technologies (MCART) whose terms of reference were:

(a) *Find out what is happening in the field of assisted reproductive technologies in New Zealand.*

(b) *Talk to interested groups and individuals to get their views on what is happening here and what should happen here.*

(c) *Gather information, from the literature available in New Zealand, about developments in other countries.*

(d) *Report to the Minister of Justice with options on the ways ahead for New Zealand in this field by 30 April 1994. (Since extended to 31 July 1994).*

The establishment of MCART represents the culmination of previous years consultation and enquiry into ART in New Zealand.

MCART has taken ART to mean those technologies, including donor insemination where conception is attempted without sexual intercourse.

BACKGROUND TO MCART

The birth of the world's first "test-tube baby" in 1978 sent a message of hope to infertile couples throughout the world. By 1984, a team at National Women's Hospital (NWH) in Auckland had announced that they too had achieved this technological milestone. However, the public debate surrounding these events was often divided and frequently ill-formed. As bio-technology developed, ethical concerns grew and there were calls for measures to manage these new reproductive technologies and their development in New Zealand.

In 1985, the Department of Justice published "*New Birth Technologies - An Issues Paper on AID, IVD and Surrogate Motherhood*" and invited submissions from interested parties. The following year, Justice also convened an Interdepartmental Monitoring Committee on ART (IMCART) with representation from the Departments of Justice, Health and Social Welfare and the Ministries of Maori, Women's and Pacific Island Affairs.

The role of IMCART was to gather information, monitor developments and advise Government on issues. IMCART also had two formal references from the Minister of Health on accreditation of providers, and from the Minister of Social Welfare on access to donor information. Submissions to IMCART drew attention to the need to formalise legal issues relating to the off-spring of ART and donor insemination (DI). Some of these were addressed in the Status of Children Amendment Act 1987.

Consumers were also becoming organised. Regional infertility groups which had become established during the late 1970s and early 1980s formed the New Zealand Infertility Society Inc in 1989.

At about this time Manatu Maori, the Ministry of Maori Affairs, established a working party to reflect on issues relating to ART and Maori. The report of the working party has been the foundation for Maori opinion in this area, while recognising that ongoing and extensive consultation is still needed. The report is found in Appendix E.

Fertility Associates in Auckland invited inspection by RTAC in 1990 and was accredited that year together with National Womens Hospital. Other units followed in subsequent years. The Royal New Zealand College of Obstetricians and Gynaecologists (RNZCOG) developed a policy that all providers of ART including DI, should be accredited with the Australian Reproductive Technologies Accreditation Committee (RTAC) in 1992.

IMCART continued its monitoring role until 1992. In 1993, at about the same time as the appointment of MCART, the Minister of Health appointed an Interim Ethics Committee on Assisted Reproductive Technologies (INECART). This Committee was formed because of the difficulties some local ethics committees appeared to be having in reaching decisions on protocols submitted by ART service providers, and a national approach was thought to be desirable.

The recent reform of New Zealand's health and disability sector has also contributed to the history and current environment. Of particular note will be the range and scope of infertility management services which will be funded publicly and how they will be provided nationally. Revision of the human rights legislation in 1993 also set new parameters for policy development.

These broad influences, together with ongoing technological developments and responses among the international community, have painted a backdrop and give a historical context for the ongoing development of ART in New Zealand.

METHODOLOGY

Our terms of reference reflect the value of the views of "*interested groups and individuals*" as well as the voices of service providers and consumers. The Committee was aware that there has been significant progress made in the history of ART in New Zealand and was keen to build on this experience.

We prepared an Issues Paper which asked for general comment as well as focusing on particular issues. This paper was sent to individuals and groups thought to have an interest in this field and to all those who had previously written to IMCART. We received 87 written submissions. These were analysed and are represented in Appendix C. Care was taken to protect confidentiality of individuals.

Furthermore we met with groups and individuals, consumers and service providers, ethicists and researchers, policy makers and the Commissioners of Privacy and Human Rights.

We also researched part of the significant body of literature on ART and relevant issues, and communicated with a variety of agencies and overseas groups on these matters.

Collectively these inputs helped us gain an overview of ART in New Zealand including; the diversity of public opinion about ART, the human face of infertility, urgent issues for New Zealand to address, possible future horizons, as well as how ART has been managed in different countries. We found this overview important to define principles which then helped guide us in the preparation of options for Government on a seemingly diverse range of issues that fall out of this topic.

Our terms of reference ask us to report on "*options*", rather than produce a perfect blueprint. We have therefore endeavoured to explore a range of future directions for the issues we have addressed. Our aim was then to evaluate these in the light of our guiding principles.

CHAPTER 2

WHAT IS HAPPENING IN NEW ZEALAND

FERTILITY MANAGEMENT

Throughout history, people have sought to manage their fertility. Contraceptive methods to avoid or postpone child bearing are found in most, if not all societies. Likewise most societies have a variety of methods to improve fertility including cultural rites, traditional remedies and social arrangements which have included forms of surrogacy and donor insemination.

INFERTILITY - DEFINITIONS

The desire to have children is strong in the majority of adults[1] and probably reflects a mixture of biological drive and sociological conditioning. Infertility has been defined as a medical condition with a physiological cause and thus requiring medical intervention. However, infertility has also been described as a social construct where the need to have children is largely determined by social attitudes and where the remedy is therefore seen as counselling, creating a society where being child free becomes more acceptable, and adoption.

The Canadian Royal Commission on New Reproductive Technologies found that in reality, the definition of infertility is a complex mixture of social and physiological dimensions[2]. Furthermore they noted that medical interventions may be used for conditions of social infertility, citing the example of donor insemination. Infertility must therefore be viewed within the context of a caring society which acknowledges the collective value of children and families.

Besides these broad definitions, infertility is also defined more clinically in order to measure its prevalence in the community. The World Health Organisation (WHO) in 1975 referred to infertility as the failure to conceive "despite cohabitation and the exposure to pregnancy for a period of two years"[3]. More

---

[1]Final Report of the Canadian Royal Commission on New Reproductive Technologies (1994) "*Proceed with Care*" Vol. 1 p.170 (77% of respondents aged 18-55 years said they had felt a need to have children)

[2]Ibid, p.174 Vol. 1

[3] World Health Organisation (1975) "*The epidemiology of infertility*". Report of a WHO Scientific Group Technical Report Series 582. Geneva WHO cited in Brander P(1991) Infertility - *A review of the literature on prevalence, causes treatment and prevention. Discussion paper 17 Department of Health, Wellington*

recently, other groups, including the Infertility Society[4] and a subsequent WHO report[5] have tended to favour a one year timeframe.

However, while a one year timeframe more closely mirrors people's expectations, Gillett demonstrated the danger of over-simplifying this measurement[6]. After one year, of all couples trying to get pregnant, 81% will have had no problem, four percent will be sterile and 15% will have delayed conception. Using this data, after two years, about 90% will have achieved conception and 93% after three years.

Gillett notes:

> *Whether conception occurs or not is a matter of chance. In the case of the more fertile the cumulative probability of pregnancy occurs quickly and the couples concerned never experience the frustration of long term failure.*
>
> *In the less fertile the average conception takes longer and so more couples experience the uncertainty of their reproductive capacity.*

Drawing the time limit at one year tends to include within the population described as "*infertile*" those couples who will achieve pregnancy given a longer timeframe. This group is sometimes defined as "*subfertile*". However, because many couples delay child bearing until their 30s when natural fertility is declining, time may be the one factor they do not have.

Besides differences in timeframe, the definition of infertility is further complicated by two other factors. Firstly, infertility should, strictly speaking, include those who have voluntarily terminated their contraceptive capacity through sterilisation. Secondly, some groups take the end point of infertility as the birth of a live baby rather than conception, thus including those couples who have difficulty continuing a pregnancy until the baby is viable outside the womb.

These definitional differences lead to wide variation in the estimation and measurement of infertility in our community.

PREVALENCE

Most estimates of the prevalence of infertility in New Zealand and other western societies have ranged between 10-20% often taking as their basis, data from national surveys in the United States. Data collected in 1965, 1976 and 1982 suggests that about 14% of married couples did not conceive after one year of unprotected intercourse[7]. Furthermore, this percentage did not significantly change between 1982 and 1988.

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[4]New Zealand Infertility Society Inc *Newsletters* (March 1990 - October 1991) 1(1)(-2(3) cited in Brander See (3).

[5]World Health Organisation (1980) "*Manual on the Investigation and Diagnosis of the Infertile Couple* Geneva WHO

[6]Gillett W (1988) "*Management of Infertility : A Changing Perspective*" NZ Med J 102 (868):248-251

[7]Mosher WD, Pratt WF (1990) "*Fecundity and Infertility in the United States*, 1965-88. Advance data (192) from *Vital and Health Statistics* of the National Centre of Health Statistics

The Canadian Royal Commission placed some importance on assessing the prevalence of infertility in Canada through national surveys.[8] They found that 8.5% of couples who were married, or cohabiting for at least one year, and who had not used contraception during that timeframe, had not conceived. If the timeframe was at least two years, 7% of couples had failed to conceive.

The differences between the Canadian and US results relate to the fact that in the USA data, those couples who had been surgically sterilised (tubal ligation or vasectomy) had been excluded from the population. When these figures were included, the USA prevalence at one year fell to 7.9%.[9]

In New Zealand, a survey of contraceptive use by 1,000 New Zealand women aged 25-44 years over the period 1983-1986 was reported by Paul in 1988.[10] She found that 3% of married women aged 25-44 years were classified as infertile but noted that definitional problems may have led to an underestimation.

It would seem that the most comprehensive data on prevalence comes from Canada. If New Zealanders are similar to Canadians, and using data from our 1991 census of Households and Dwellings, estimates of prevalence can be obtained using the same methods as those used by the Canadian Royal Commission. For women aged 18-44 years who are married or in a de facto relationship of at least one year duration about 32,300 [95% CI 26,600 - 34,200] will not have conceived. Of those whose marriage or relationship is of at least two years duration, 25,500 [95% CI 20,400 30,700] will not have achieved a conception.[11]

These couples represent between 50-60,000 New Zealand adults, voters and taxpayers who are directly affected by infertility. Furthermore the Canadian Royal Commission also noted that "*43% of those surveyed knew someone in their immediate family or among friends who had experienced an infertility problem*"[12].

DEMAND FOR SERVICES

During the last decade, there has been an increase in consultation for the diagnosis and treatment of infertility. While some would have us believe there is an epidemic of infertility occurring, the evidence is scarce. The increase in demand is most likely to represent a combination of several factors;[13]

- increasing public awareness about infertility and its treatment;
- the tendency to delay childbearing;
- the ageing of the "*Baby Boom*" generation;
- increasing pelvic sepsis and surgery; and

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[8]Canadian Royal Commission Report Vol. 1 p.180
[9]Ibid, p.189
[10]Paul C et al (1988) "*Contraceptive Practise in New Zealand*" NZ Med J 1988; 101:809-13
[11]For methodology - See Canadian Report Vol. 1 pp. 195-197
[12]Canadian Royal Commission Report Vol. 1 p.179
[13]Brander P (1991) "*Infertility - A review of the literature on prevalence, causes, treatment and prevention*". Discussion Paper 17 p13, Department of Health, Wellington

- increasing numbers of service providers;

Not all couples who experience infertility present to health services, probably fewer than 50% attend their family doctors for investigation and management.[14] Many are referred on for specialist investigation and treatment.

However, a British study showed that one in six of the study population sought specialist help at some time in their lives because of infertility which lasted an average, two and a half years.[15] A subsection of this group go on to consider ART.

It must be remembered that infertility and subfertility are common terms for a group of disorders which have a variety of causes, treatments and outcomes.

In New Zealand, the investigation and management of infertility occurs at all levels; primary, secondary and tertiary through a mixture of private and public funding. At a primary level, laboratory investigations and the consultation subsidies are publicly funded while the client also contributes towards the cost of the consultation. Referral to secondary (specialist) care can be through the public hospital system, where clients pay a set fee for outpatient visits. Further investigations, including surgery, are state funded.

Specialists' care can also be sought and provided through the private health care system where waiting lists are likely to be shorter and choice of specialists can be exercised. Drug therapy for some disorders can be prescribed by specialists under s.99 of the Medicines Act and is state subsidised.

Furthermore, at a tertiary level, ART services are available though the public health system within guidelines and usually extensive waiting lists in several different centres. A variety of ART services are also provided by private providers.

This mixture of public and private provision of health services is important to recognise along with its strengths and weakness. Because many cases of infertility are not absolute, the relative success of new treatments must be compared with the natural outcome of an untreated population. Also it is possible that those treatments publicly funded, especially at a secondary level, may be over utilised in response to the need to be "*doing something*".

Our inquiries also note that infertility services are, in almost all cases not covered in health insurance policies. Many consumers felt unhappy about this. The Human Rights Commission is following up on the appropriateness of this decision.

A summary of services, service providers, conditions and locations follows:

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[14]Page H (1989) "*Estimation of the Prevalence and Incident of Infertility in a Population : A Pilot Study*". Fertility and Sterility Vol. 51; 4, pp. 571-577. [37% of a group of 43 UK women with infertility had sought help from their family doctor]

[15]Hull et al (1986) "*Population Study of Causes, Treatment and Outcome of Infertility*" Br Med J 1986; 291:1693-7

Location	Provider	Services	Conditions
Auckland	Greenlane Infertility	120 patients per annum Full range IVF DI & AIH ICSI pending	National Service Outpatient clinic fees, some drug charges Usual criteria for public service Waiting list - IVF 2-2½ weeks - Clinic appointments 6 - 8 weeks
	Artemis	Full range IVF DI & AIH ICSI	Private
	Fertility Associates	Full range IVF ICSI DI & AIH	Private
Hamilton	Fertility Associates	DI & AIH	Private
New Plymouth	Private Specialist	DI	Private
Wellington	Fertility Associates	DI & AIH 3 x year IVF only Otherwise referred to FA Auckland	Private
Palmerston North	Private Specialist	DI	Use sperm from FA (Wellington)
Masterton	Private Specialist	DI	Use sperm from FA (Wellington)
Christchurch	Christchurch Womens Hospital Unversity of Otago Christchurch Medical School	100 cycles per annum "free" up to 3 cycles Full range IVF DI & AIH ICSI Parallel user-pays service	South Island area Usual criteria for public service Outpatient clinic fees No drug charges Waiting list - 600 couples
Dunedin	Health Care Otago IVF Otago University of Otago Medical School	Public 70-90 cycles pa Full range IVF DI ICSI pending	Southern RHA area $500 first IVF cycle $1,500 second CHE subsidy No waiting list No empty criteria
Nelson	Private Specialist	DI	Use sperm from Dunedin or Christchurch

Abbreviations:
DI donor Insemination
AIH artificial insemination by husband
IVF Invitro fertilisation
ICSI Intra cytoplasmic sperm injection

INFERTILITY CAUSES AND PREVENTION

As noted earlier, there are many causes of infertility and each has a different management protocol and likely outcomes. Of the causes, some are well-established while others are still debated. Furthermore, 10-30% of couples will have multiple causes. The following table notes the variety of causes and their prevalence and their likely outcome expressed in pregnancy rates.

REF	CAUSE	PREVALENCE (%)	OUTCOME PREGNANCY RATE (%)	NOTES
f *	Ovulatory Failure	15-30%	~80%	Increases with increasing age of women
*f**	Tubal Damage	20%	~20%	Many need IVF. STD's may account for 40%
*f**	Semen Factor	20-30%	20-80%	Less than 20% sterile New treatment ICSI
*f**	Endometriosis	5-25%	40-85%	Varies in severity Contributes to subfertility
*f**	Cervical Factor	less than 5%	~25%	Can be treated with AIH with some success
*	Immunological causes	less than 5%	variable	
*f**	Coital Failure	less than 10%	variable	?ICSI
f	Luteal Phase Deficiency	less than 10%	40-50%	
*f**	Unexplained	15-30%	~70%	
*f**	Multiple	15-30%	variable	

Abbreviations:
AIH - Artificial Insemination by Husband
ICSI - Intracytoplasmic Sperm Injection
IVF - Invitro fertilisation

Sources:
* - Brander P (1991) "*Infertility - A Review of the Literature on Prevalence, Causes, Treatment and Prevention*" Discussion Paper 17 - Department of Health Wellington
f - Jones H et al (1993) "*The Infertile Couple:*" New Eng. J Med 329(23) 1710-1715

Many submissions to us stress the importance of efforts to prevent infertility to reduce the demand for expensive and intrusive tertiary health services. We note however that this is not an "*either prevention or ART*" scenario.

The preventable cause most often quoted to us was sexually transmitted diseases. However, STDs are still a minority cause of tubal disease and probably contribute to less than 10% of all cases of infertility[16] [17]. Nonetheless, STDs and their role in infertility have a significant public profile which sometimes brings a stigma to infertility.

Besides STDs, other factors predispose to infertility. The main factors include:

- Increasing age, especially amongst women
- Cigarette smoking
- Testicular trauma
- General lifestyle factors including extremes of body weight, excessive exercise, drug and alcohol use, choice of contraceptive and environmental toxins.

In recent years, there has been increasing emphasis for individuals to be accountable for their own wellbeing. However we believe that people have the right to information to assist in issues of informed choice. Furthermore the interests of the public health of New Zealand will best be advanced by investing in efforts to impress on teenagers that they have a precious gift in their fertility which needs protection.

We heard of an intervention in schools which discussed fertility with teenagers and noted that most expected to have children later in life[18]. This expectation laid the foundation for a discussion on protecting fertility which was reportedly well received and had an entirely different focus from the usual sexual health care messages given to teenagers. We believe however, that the two messages are necessary and complementary and the issue of fertility should be incorporated into the health education syllabus in schools.

We recognise that health promotion amongst teenagers has inherent difficulties but note that intervention at any later stage may be too late and draw attention to the success reported by innovative programmes using peer-educators by the New Zealand Family Planning Association.

While only a small proportion of cases of infertility have causes which can be identified as preventable, there is much evidence relating to several factors which

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[16]Peek J et al (1990) "*Prevalence of chlamydia antibodies in women with tubal disease : impact of chlamydia trachomatis on demand for invitro fertislation*" NZ Med J 103 (884) 63-65

[17]Brander P (1991) see above in chart refers, p19. Brander P (1991) "*Infertility - A review of the literature on prevalence, causes, treatment and prevention*". Discussion Paper 17 p13, Department of Health, Wellington

[18]Fertility Associates Auckland (1993) personal communication

contribute to infertility in our society. We acknowledge that, for many people, infertility causes extreme distress and for this reason efforts should be made to address the risk factors known to predispose towards infertility.

CURRENT REGULATION

Currently ART services in New Zealand are regulated by a mixture of general statutory provisions, professional self-regulation, health service controls and market forces.

Statutory Provisions

In 1987, Parliament passed the Status of Children Amendment Act, to clarify issues relating to the legal status of offspring born as a result of donated gametes. Prior to the enactment of this Act, uncertainty surrounded the legal status of the child and the legality of birth registration. The Act made it clear that a donor will not be treated as the legal parent and faces no legal consequences (eg child support). While some have criticised the Act for reinforcing a fiction about the child's "*true*" ie, genetic, parentage, there was little doubt at the time that the interests of offspring demanded certainty.

Since 1987 there has been no legislation dealing specifically with assisted reproduction, but it does not follow that legislation has not affected the area. The current legal framework which governs medical practice includes the Health and Disability Services Act, the Medical Practitioners Act and the Medicines Act. Other health professionals are covered by the Nurses Act and the Medical Auxiliaries Act. The Code of Health and Disability Services Consumers Rights in the Health Commissioner Bill also provides a mechanism for ensuring the rights of ART clients.

Furthermore, public law statutes such as the Human Rights Act, the New Zealand Bill of Rights and the Privacy Act all create an environment where the provision of ART services is governed.

Professional Self Regulation

Professional self regulation plays a central role in the regulation of ART. In 1992 the RNZCOG formulated a policy that all providers of ART, including DI services, in New Zealand, be accredited with the Australian Reproductive Technologies Accreditation Committee to set minimum professional standards and allow peer review.

Service providers have participated in this accreditation system and reported positively about belonging to a larger group of professionals in the same rapidly developing field. Of particular note, RTAC provides procedural guidelines in such matters as the professional qualifications required of staff of the providers, the prevention of infectious diseases, the collection of information and the provision of support services including counselling.

Most providers and consumers are quick to acknowledge that RTAC is Australian focused and New Zealand guidelines need to be framed. For New Zealand providers, two members of RTAC visit together with a New Zealand specialist, nominated by the Department of Health in consultation with the RNZCOG, and a New Zealand consumer. However many providers feel that local guidelines need to be appended to RTAC accreditation to best suit New Zealand history, culture, policy and practices.

While RNZCOG has been charged with the development of these guidelines, they have yet to surface and it is likely that the College will need organisational assistance to produce them. However, the RNZCOG has formally adopted the policies outlined in the Manatu Maori paper to IMCART and promotes these to RTAC.

Furthermore, the RNZCOG is hampered in other aspects of its role of professional self-regulation. Its major role is professional quality assurance but it has no ability to enforce the standards that it sets among its members, let alone non-members. Back-up policies by the Medical Council, which could affect the registered status of providers, would need to be put in place to ensure the safety of New Zealand consumers.

Health Service Controls

Health service controls function through a variety of mechanisms, including legislation and regulation mentioned previously. They are also applicable to the public provisions of ART services through negotiated purchase agreements provided by the Health and Disability Services Act. Although not explicit in the Act, it can be assumed that providers of services which do not voluntarily meet standards would find this disadvantageous in their negotiations. Providers who have taken the initiative to become accredited to organisations which promote quality and healthcare standards are likely to find this advantageous.

Market Forces

The New Zealand Infertility Society and regional infertility societies play key roles informing and educating consumers in our society. It is the experience overseas that this type of approach can significantly affect the business of providers who, for example, do not become accredited. In such a way, they can influence consumer decision-making and inform consumers about the standards of services they can expect.

ETHICS IN ART

The ethical aspects of ART are considerable. They vary along a spectrum of public concern for technology in the wrong hands, the dignity of human life and relationships and the beginnings of life. The human aspects of ART make the

ethical questions more poignant and the need for management of technological development more certain.

We found that many providers have recognised the need to question themselves, their procedures and their decision making. Some have set up internal multisectorial ethics committees for ongoing review. Others seek peer review.

Regional Ethics Committees were established under Area Health Boards and their key role was to approve research proposals and new treatment protocols. The committees were continued under the recent health reforms and the Health and Disability Services Act provides for the establishment of a National Advisory Committee on Health and Disability Services Ethics.

In 1993, it was reported that some local ethics committees were having difficulty with proposals and protocols from the providers of ART services. The Minister of Health appointed the Interim National Ethics Committee on ART to provide a national focus and to ensure a consistent approach.

Recently, in response to a review of ethics in the health sector and as part of the establishment of the National Advisory Committee on Health and Disability Services Ethics, the Minister of Health announced the continuance of INECART as a stand alone committee accountable to the Director General of Health.

The boundaries of the various roles of national policy making, advising local committees and practical decision making have still to be worked out. However, there can be no doubt that consumers, providers and the public alike, recognise the fundamental importance of ethical issues to ART.

RESEARCH

Like all new and developing technologies, ART is closely aligned with research. Research has shown how to improve all aspects of these technologies. The vast majority of the research which is occurring relates to the technical aspects of ART procedures. This has been prioritised during the development and refinement of these technologies and even today seeks to extend boundaries. For a number of reasons, this biomedical research is more likely to obtain funding.

On the other hand, relatively little research relates to the social aspects of our current policies and practices. These social research projects are more likely to need a longer timeframe and thus be relatively expensive. Because we in New Zealand are operating policies, such as openness in donor insemination, which are not widely practised by other countries, it would be negligent not to attempt to document the impact of these policies on our social structures and family relationships.

Furthermore, as ART is in part state funded and state sanctioned, the state should consider its role in monitoring the social outcome of these policies and services.

PRIVACY AND INFORMATION

Traditionally, in many societies, donor insemination through ART has been anonymous. New Zealand providers have responded in less than a decade to the issue of openness. They have listened to those involved in the adoption debate and they have considered the policies promoted by Maori, that knowledge of whakapapa (geneology) is a Treaty right which allows Maori to exercise not only cultural rights to land and marae but also constitutional rights such as voting on the Maori electoral roll.

Many New Zealand providers have pro-actively taken up the challenge of these policies and begun to recruit identifiable donors, ie those who are willing to be identified at a future time and usually through a third party. Accepting this practice has required courage and a change in the way in which the donor population is approached and donors recruited. However, some providers, especially those in more conservative regions of New Zealand, still recruit anonymous donors. Furthermore not all recipients of DI intend to discuss the biological origins with their offspring.

This lack of consistent policy nationally may need to be considered within the parameters of access to donor information, the management of donor information, the rights of donors and offspring and continuing public education towards openness within families.

ACCESS - HUMAN RIGHTS

The stated aim of many providers has been to treat the physiologically infertile, and in particular DI is said to be used for the treatment of male infertility. Because of these aims, most providers to date have only treated couples in stable heterosexual relationships of at least two years duration.

Over recent years, providers have been approached by single women and lesbian couples, who while not physiologically infertile are socially infertile, requesting donor insemination services. Most providers have forwarded proposals to the appropriate Ethics Committee for an opinion and signalled to us that this was an issue for urgent attention.

While these consumers could conceive without ART, we recognise that ART services are especially designed to minimise the spread of infectious diseases like HIV/AIDS and hepatitis. Moreover by using ART and the policies which regulate it, the offspring may well have the best chance for obtaining information about his or her genetic origins in future years. For these reasons the wellbeing of the offspring may best be protected with DI through a provider who operates under the same regulations as ART providers.

However, several issues arise to add to this debate. Firstly, the Human Rights Act 1993 which plainly states that people should not be discriminated against on the basis of age, marital status or sexual orientation. Secondly, what of the rights of donors, especially now when many are being recruited on the "Fathers for Fathers"

basis? Thirdly the limited public resources in the area of ART is an issue that is keenly felt by those couples disabled by physiological infertility. How will these resources be shared with a greater population of infertile people if those who are socially infertile are included in the group eligible for state funded assistance?

The implementation of the Human Rights Act as it stands will require a review of current policies and time to reposition current practices. This will be assisted by informed public debate.

CHAPTER 3

INTERNATIONAL DEVELOPMENTS

1. INTRODUCTION

One of our terms of reference was to find out what was happening in the field of ART overseas. There were two aspects of this:

(a) what technological advances are being made; and

(b) what policy and legal responses there have been to ART.

Our main source of information on these points has been the literature available in New Zealand. However the Committee has also been in direct contact with key figures overseas and has gained some impression of the range of international activities and responses.

The value in studying what is happening elsewhere is not a matter of curiosity but rather lies in the light that such a study may shed on policy-making in this country. We therefore have not set out to list each country and give a comprehensive rundown on all the information available. Instead, we hope to convey something of the wide spectrum of approaches to ART. This spectrum ranges from a laissez faire approach through to detailed controls and bans. In between there is such a wide variety of alternatives that it is impossible to state with certainty whether there are any international trends. With that caution in mind, we note that there is a general trend towards clarity in the legal status of children born as a result of ART. As New Zealand dealt with this issue in 1987, we can be seen as in the mainstream of international action on this issue. Other significant issues - supervisory bodies, access to genetic information, surrogacy, disposal and research on embryos etc - have not led to uniform policies.

The lack of a common mind internationally can lead to some distinct difficulties. If research is banned in one country but not in another, research can obviously still proceed, especially where multi-national companies and ventures are involved. The banning country may however ultimately gain by any research done elsewhere, a process the Canadian Royal Commission referred to as "*ethical dumping*" - "*taking the moral high road by banning research but later benefiting from the results of research conducted elsewhere and imported into medical practice in Canada*" (p 15). A similar problem is one country's banning of certain procedures which are allowed in others, leading to "*reproductive tourism*" (Canadian Royal Commission p 21), whereby those who can afford it, travel the world to find the services that they cannot access in their home state. From one point of view, reproductive tourism may be little different ethically from any other kind of tourism, but

awkward private international law consequences could arise if, for instance, a child's status is recognised in one jurisdiction but not another, or rights with respect to embryos differ from place to place and New Zealanders are engaged in an international battle with a clinic located in an overseas country. Whether the fulfilling of dreams to have a family with children should depend on wealth and world searches is a debatable matter.

There is a case for greater international co-operation in working out rules on ART. Issues such as the export and import of gametes and embryos may well merit world-wide negotiation. In Europe a draft European Convention on Bioethics which will cover ART among other things has been prepared. However the wide differences in approach already adopted by countries throughout the world - even as between the states of Australia and New Zealand - make prospects for international agreement largely forlorn. Added to this are the widely differing religious and cultural attitudes taken throughout the world. Islam for instance is quite distinct from Catholic Christianity.

In the end, New Zealand must proceed to develop policies which suit our conditions. We can be guided by what is happening elsewhere but there is little to be gained by mimicking other countries' efforts for that reason alone.

2. TECHNOLOGICAL DEVELOPMENTS

The development of biotechnology surrounding ART has occurred on many fronts and includes some of the more dramatic aspects which have captured media attention. This underlines the fact that expanding technological horizons demand informed public debate and a framework of ethical decision-making in which all parties, including the public, can have confidence.

Gametes

Recent technologies have improved several aspects of gamete harvesting, storage and maturation.

In men, a critical number of live, motile sperm are usually necessary to reach the egg, dissolve its outer layer and finally one sperm achieves fertilisation. Today this process can be bypassed using a technique called intracytoplasmic sperm injection (ICSI) where low sperm counts and poorly mobile sperm can achieve conception by being directly injected into an egg. Furthermore, if a semen sample fails to yield sperm or indeed cannot be obtained, a testicular biopsy can produce immature sperm or sperm precursors which can also be used in this process. This technique needs to be used in conjunction with ART, but offers hope for many men who previously had to resort to donor insemination.

Ova have also been the subject of research and development. Super-ovulation regimes are being developed and trialled, to increase the yield of mature ova picked up at each cycle. However, these regimes are not without risks and other

researchers have developed technology whereby ova in ovarian tissue can be matured in vitro. Thus ovarian tissue from a biopsy or donor could yield a significant number of mature ova.

In the United Kingdom, the Human Fertilisation and Embryology Authority (HFEA) has recently released a discussion document which admits a shortage of ova exists for both treatment and research. The document "*Donated Ovarian Tissue in Embryo Research and Assisted Conception*" sought public debate and submissions on the harvesting of ova from live donors, the dead bodies of women and girls and from aborted female fetuses for use in ART treatments and/or research.

While the HFEA questions whether or not the donation of ovarian tissue should be seen as similar to other blood and organ donation, we believe that donation of genetic material requires special consideration. Furthermore, the donation of material from dead people also needs in-depth ethical review as would any proposal to use fetal tissue from aborted fetuses.

Until recently, the storage of ova was considered problematic and this resulted in the formation and storage of embryos with their associated ethical and legal complexities. Researchers have recently confirmed the ability to freeze and thaw human ova. A shift to the storage of gametes instead of embryos may mean fewer ethical issues relating to the use, donation and disposal of spare embryos but is likely to create pressure to be able to create embryos for research purposes.

Embryos

There have also been technological developments which raise issues of the treatment of the early embryo. One such issue is sex selection. Sex selection may be desired for medical or social reasons. Socially, couples who already have children of one sex may wish that their next child be of the other sex, and despite anti-discrimination laws, many cultures value men and women differently. Medically, some diseases are sex-linked, that is they are carried by some women and affect their sons. These diseases range from not very serious, such as most forms of colour blindness, to serious diseases such as haemophilia and some rare muscular diseases.

Sex selection can be achieved before conception where intercourse can be timed to slightly increase the chances of a child of the preferred gender. Some groups overseas have claimed success with a technique known as sperm sorting.

> *The rate of success for this technique is not proven: Current proponents of the technique claim that there is approximately 80% chance of producing a child of the intended sex. The chance through normal sexual intercourse is about 50%.*[1]

Sex selection can also be used in association with ART by identifying the gender of the embryos and transferring to the uterus only those of a specified gender. This

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[1]HFEA (1993) "*Sex Selection*" Public Consultation Document, London

method is likely to be very accurate but requires the creation of embryos, interference with the embryo to determine gender and ART to transfer selected embryos back into the womb.

Some reasons for sex selection may be ethically more acceptable than others and these aspects are likely to need consideration in New Zealand in the near future.

Ongoing research on embryos is trying to establish the best time to transfer the embryo(s) back to the uterus. Most centres transfer at about two days after fertilisation but it seems that allowing the embryos to grow in vitro until about five days sorts out the more robust embryos that are likely to develop fully. Changes in protocols such as this may eventually influence the number of embryos being replaced.

Technology is also developing and refining to enable micro-manipulation of genetic material including "*gene insertion*". Its application in horticulture and agriculture has been hailed by many but the transfer of this technology to humans is of concern to many who believe that the sanctity of the human genome should be protected. Other technologies which could lead to cloning and animal-human hybrids have been banned by statute in many countries (see below).

Fetal Tissue

Some aspects of technological development relating to fetal tissue have been discussed above including harvesting ova from aborted fetuses. While many people feel this practice is repugnant, others are keen to gather fetal tissue in their striving for biomedical advancement. Fetal brain cells have been refined and used to treat people with Parkinson's Disease. Furthermore tissue from a fetal pancreas could be grown to produce pure human insulin for diabetics.

While some people may consider that the harvest and utilisation of fetal tissue is a breach of the concept of treating human tissue with dignity and respect, others may feel that the future benefits the research may bring should override this consideration. Informed public debate will be necessary.

Pregnancy

The physiology of uterine receptivity, implantation and early pregnancy is complex and research is occurring on environmental issues which will improve the uptake and implantation of fetuses. Not all of the research in this area is "*high tech*". Greenlane Infertility (NWH) have shown a reduction in miscarriage rates and early pregnancy loss in ART clients by attendance at regular monitoring clinics and physiotherapy programmes during the first 2-3 months of pregnancy.

There has been significant media coverage of Italian research and treatment of post-menopausal women with ART. While the debate has raised issues such as "*is*

it good for a child to have an elderly mother?" this question is not asked of men. A more fundamental question would ask if it is good for an elderly woman to become pregnant, give birth and raise a child. This is another complex issue that will need consideration at some time in our future (see also our later chapter "*Discrimination*").

Gene Therapy and Genetic Engineering

Discussion is proceeding around the world on scientific advances in the field of genetic engineering. Gene therapy - the administration of genetic material into a human patient with the intent of correcting a specific defect - is a major aspect of this. The ethics of somatic gene therapy and the more far-reaching germ line genetic engineering has been debated among philosophers and scientists. In New Zealand, a special task force operating under the aegis of the Health Research Council is about to report on this subject.

Many of these technologies are criticised for "*going too far*" and being against a natural order of life. However, those wishing to develop them argue that travel by jet aeroplane is also against the natural order, yet it is commonly accepted and utilised. Whether it is the concern for tampering with human reproduction, the human genome or human life at its various levels of development, there is no doubt that these technological developments demand a system of accountability and regulation within ethical and legal frameworks. Different countries have approached developing issues in a variety of ways.

3. LIBERAL APPROACHES

Many jurisdictions have not developed detailed policies on ART but have instead left the ordinary law to control the activities of providers and researchers. Examples include New South Wales and most of the states of the United States.

In the US, regulation is on a state by state basis. About half the states have legislated to deal with the status of children born as a result of donor insemination (the pioneering states being California, Georgia, Kansas and Oklahoma) and some statutes sought to limit the operation of the status rules to those inseminations which had been performed by physicians (a provision of this kind is found in s 5 of the Uniform Parentage Act, which was promulgated in 1973 by the National Council of Commissioners on State Laws but has effect only as a model to guide law-making bodies). Some states such as Texas have also dealt with status issues arising as a result of oocyte donation. Ohio has legislation with requirements for screening donors and Louisiana has a law which defines an embryo and among other things bans the sale of embryos and the creation of embryos solely for research. Some other states have various forms of regulation of ART. For example, an Idaho statute requires that artificial insemination not be performed on a woman without her prior written request and consent and that of her husband, such consents to be filed with the State Registrar of Vital Statistics.

The Uniform Status of Children of Assisted Conception Act (USCACA) was released by the National Conference of Commissioners on Uniform State Laws in 1988 and is a model for legislatures to follow. Its most interesting provisions relate to surrogacy and offers two alternative approaches, one which provides for the acceptance of surrogacy agreements so long as they receive judicial approval and the other which makes such agreements void but also makes the birth mother the legal mother where there is such an agreement. So far, USCACA has not been followed except in a modified version in Virginia which allows for some surrogacy contractual provisions which are not for gain and in North Dakota which bans surrogacy. Other states have independently of USCACA legislated on surrogacy, some declaring surrogacy contracts invalid (eg Arizona, Indiana, Kentucky, Louisiana, Michigan. New York and Utah), some prohibiting commercial involvement in surrogacy and some recognising surrogacy agreements (in addition to Virginia, Arkansas and New Hampshire). Where the legislation is silent on ART, issues may have to be determined by the courts. This has happened in a number of surrogacy cases, one of the most recent being the decision of the Supreme Court of California in *Johnson v Calvert*[2] in which it was held that where the birth mother was not the genetic mother of a child, the law would recognise the genetic mother as the child's "*natural mother*". Other issues to come before the courts have included the legal status of a child born as a result of egg donation (held that the gestational mother is the legal mother), the disposition of frozen embryos where the progenitors' marriage broke down (held that normally the party wishing to avoid procreation should get custody of the embryos), whether a testator can bequeath his frozen sperm to his cohabitant (held yes), whether damages could be awarded where a doctor deliberately destroyed an embryo (yes), and whether a clinic must hand frozen embryos over to a new clinic that a couple wish to move to (yes).

The US position is a mixed one, with varying responses from state to state. The overall pattern however is one which leaves the practice of ART largely to market forces without specific regulation, with the result that issues are picked up by the courts, or consumers and professional bodies. In 1992 for example the National Advisory Board on Ethics in Reproduction (NABER) was established by the American Fertility Society in concert with the American College of Obstetricians and Gynaecologists but it does not have any regulatory function.

4. MIXED APPROACHES

The approaches adopted in Britain and in some Australian states might be considered a middle course, a mixture of procedures within which technology can proceed and outright bans for certain specific activities.

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[2]851 P 2d 776 (1993)

Victoria

Victoria was one of the first jurisdictions ever to have comprehensive legislation on ART and followed reports by the Waller Committee. The Infertility (Medical Procedures) Act 1984 bans cloning, mixing human and animal gametes, renders surrogacy contracts void and outlaws payments for surrogacy. ART, with the exception of donor insemination, is generally illegal unless done at a hospital approved by the relevant Minister. Artificial insemination may be performed only by medical practitioners and must be accompanied by approved counselling. The Act establishes a Standing Review and Advisory Committee which has representation from the fields of philosophy, medicine, religion, social work, law and community affairs but no one representing consumers. It has the functions of advising the Minister on infertility and approving embryo experimentation. It is interesting to note that there are two principles which the Committee must have regard to

(a) *the principle that childless couples should be assisted in fulfilling their desire to have children* and

(b) *the principle that human life shall be preserved and protected at all times* (human life is not as such defined).

Other Australian States

The Victorian model is an early one even though it is only ten years old. Other Australian states which have legislated have tended to adopt different structures. Tasmania and Queensland have both passed restrictive surrogacy laws, which apply not only to ART but also surrogacy by natural means and their drafting is so wide that it could outlaw certain cultural practices which in this country might be protected under the Treaty of Waitangi. Other states have established special statutory bodies to licence and oversee infertility services. For example, the Western Australian Human Reproductive Technology Act 1991 provides for the Western Australian Reproductive Technology Council which has wide membership including

(i) adequate representation of the interests of women, of parents, of the children born of reproductive technology, and of participants in reproductive technology;

(ii) expertise in reproductive technology;

(iii) relevant experience in public health matters; and

(iv) relevant ethical guidance.

Assisted reproduction (with some exemptions for donor insemination) and storage of gametes and embryos cannot generally be carried out without a licence and

breach of these rules constitutes a criminal offence. Although the actual licensing is the responsibility of the Commissioner of Health, the Commissioner acts on the advice of the Council. The Council has several other important functions: to advise the Minister on ART, to handle research applications (research destructive of an embryo cannot be approved), to facilitate research into the causes of infertility (*"adequate attention being given both to female and to male infertility"*) and into the social and public health implications of ART, to promote public debate, to consult with various bodies inside and outside the state, and, perhaps one of the most important functions, to prepare a Code of Practice on ART. The Act sets out in detail the procedures for implementing the Code, a wide range of matters to be dealt with in the Code (including privacy issues and the recognition of ethics committees) and the principles to be embodied in the Code (including consent, restrictions on the purposes for which embryos may be created and stored, and the regulations of gametes and embryos - note that gametes are referred to *"as though personal property"*). Non-compliance with the Code may go towards establishing liability and may be taken into account when an application for a licence is being considered.

The approach found in the South Australian Reproductive Technology Act 1988 is similar to that in Western Australia but the legislation is far less detailed. The *"South Australian Council on Reproductive Technology"* has similar functions to the Western Australian body but in formulating a *"code of ethical practice"*, the *"welfare of any child to be born in consequence of an artificial fertilisation procedure must be treated as of paramount importance, and accepted as a fundamental principle"*. The Western Australian Act simply states in its objects section that the welfare of the child is something *"properly to be taken into consideration"*. The South Australian code is also bound by four other points: embryo flushing is prohibited, the gamete providers of an embryo have the right to decide on the embryo's disposal, an embryo must not be stored for more than ten years, and an embryo may not be developed outside the human body beyond the stage when implantation would normally occur.

Human Fertilisation and Embryology Act 1990

Britain has extensive laws and procedures on ART, largely coming into force as a result of the passage of the Human Fertilisation and Embryology Act 1990 (HFEA). While to European eyes the Act appears liberal, partly because it permits research on embryos up until the primitive streak appears (defined as 14 days after the gametes are mixed) others may classify it as involving major State intervention.

In 1984, the report of a Committee of Inquiry into the subject was published, popularly known as the Warnock Report after its chair, Dame Mary Warnock. This report has been the major influence in shaping policy and laws in Britain. The main thrust of the report was agreement that there should be a system of licensing and regulation of ART. The questions of surrogacy and embryo research attracted dissenting statements from some members of the Committee.

Early parliamentary intervention occurred when the Surrogacy Arrangements Act was passed in 1985, aimed essentially at outlawing commercial involvement in surrogacy. The 1990 Act added a further provision to the 1985 Act by making a surrogacy arrangement unenforceable "*by or against any of the persons making it*". The actual practice in Britain is however rather different from the impression created by these statutory provisions. Several surrogacy agencies exist and are able to operate by being set up just within the legislative guidelines. Surrogacy occurs within licensed providers and payments to cover expenses are made, but, as a matter of practice, each case of surrogacy is first approved by an ethics committee. The issue of overall regulation of ART was given a longer gestation period by the Government, until the 1990 Act was eventually passed. The pivot of the Act is the establishment of the Human Fertilisation and Embryology Authority. The Authority has power to grant licences for treatment (including the odd item of mixing sperm with the egg of a hamster), for storage, and for research. As at the time of its 1993 annual report, the Authority had licensed 65 centres for IVF and 37 for DI only. Thirty-two research and 8 storage licences had been issued. Five licence applications including two research applications had been declined.

The Authority maintains five committees: licensing and fees committee, code of practice committee, information committee, organisation and finance committee, and the committee on social and ethical issues. A revised code of practice was released in June 1993 and among publications for public consultation have been ones on sex selection and use of fetal tissue. The public response to the latter discussion paper has been overwhelming, with the document forming the basis for discussion in many community groups up and down the country.

One of the problems facing the Authority and those using ART is the cost of the Authority's work. The Authority is expected to a great extent to be self-financing, which means that ultimately costs are passed on to consumers.

5. CONSERVATIVE APPROACHES

Europe is the location of some of the most conservative laws in the world, although some European countries, notably Italy, Spain and Greece, have virtually no controls at all.

Austria prohibits all forms of donation of gametes and embryos except for donor insemination in vivo. DI is banned even where the intended father is fertile but has a hereditary disease which may be passed on to his children. No more eggs may be collected than are required for the particular treatment cycle which "*renders cryopreservation almost redundant*" (Morgan and Bernat "*The Reproductive Waltz: the Austrian Act on Procreative Medicine 1992*" [1992] Journal of Social Welfare and Family Law 420). Where embryos are stored, they may be stored for only one year and then allowed to die. In contrast, Germany allows surplus embryos to be transferred to someone else. In Austria, ART procedures are limited to married couples and those living in de facto relationships. Destructive research on embryos is prohibited. The German scheme is fairly similar, prohibiting fertilisation other than for the purposes of pregnancy, and only for the purpose of re-implantation in

the woman who produced the egg. Egg and embryo donation are thus effectively forbidden. Destructive embryo research is punished harder than in Austria, with imprisonment up to three years being possible.

France has recently passed restrictive legislation. Among other things, it limits ART to married couples or de facto partners who have cohabited for at least two years. Women must be "*of child-bearing age*", thus outlawing pregnancies for post-menopausal women.

6. THE CANADIAN ROYAL COMMISSION

The most recent international development of great significance for our report has been the publication of the report of the Canadian Royal Commission on New Reproductive Technologies. The title of the report "*Proceed with Care*" is indicative of the approach taken by the all-female Commission - that Canada should move forward into the new scientific reality but with a system for managing the technologies which has clear limits based on what society considers to be acceptable activities (p 10). Its conclusions were based on three considerations (p xxxi):

> *a set of explicit ethical principles, the values of Canadians, and a conviction that offering any medical procedure as a service must be based on evidence that it works.*

The Royal Commission was established in 1989 with a large budget and a team of assistants, including over 300 researchers at institutions across Canada. It produced a range of discussion papers and a final report of nearly 1300 pages. It must be classified as the most exhaustive examination of the issues surrounding assisted reproduction anywhere in the world. It received submissions, held public hearings, held symposia and tapped public opinion by personal interviews, focus groups, phone interviews and questionnaires. Over 40,000 individuals contributed to the Commission's work. As a result, the report is a mine of information, statistics and ideas, which suitably translated to New Zealand conditions, should inform debate here. The Commission advanced two main overall recommendations, amidst a host of more detailed ones (p xxxii):

(a) Legislation should ban certain activities, including "*using embryos in research related to cloning, animal human hybrids, the fertilisation of eggs from female fetuses for implantation, the sale of eggs, sperm, zygotes or fetal tissues, and advertising for, paying for, or acting as an intermediary for preconception (surrogacy) arrangements.*"

(b) The federal Canadian government should establish a regulatory and licensing body to be called the National Reproductive Technologies Commission, with licensing being mandatory for those offering reproductive services to the community.

7. CONCLUSION

Our study of what is happening overseas indicates that, while many technologies have become standard procedures, new scientific discoveries are outstripping familiar ethical and legal categories. From one point of view, these advances are exciting and are a sign of humankind's constant quest for knowledge and progress. From another point of view, they reach so deeply into our understanding of what it is to be human that a point may be reached where humankind says "*no more*" or "*wait*". Science and metaphysics do not always move at the same pace.

The world survey of legal responses to new technologies indicates little consistency in approach. This may be explained in part by countries' different histories and cultures. But it also reflects the sheer difficulty in drawing universally acceptable boundary lines. In New Zealand, we should be ready to respond in the light of our own culture and history. New Zealanders can look overseas for inspiration but cannot expect to find the perfect solution.

CHAPTER 4

PRINCIPLES - NAVIGATION POINTS

The development of policy and practices in assisted reproduction should be done on the basis of widely accepted principles. As we navigate the future, we need beacons and stars to guide us. This will often be a voyage of discovery. The seas will sometimes be rough, at other times smooth.

We have to acknowledge that we are not always all travelling on the same boat. We live in a pluralist society and finding beacons which all can trust is never easy. Different groups have their own beacons. We all need to understand the different perspectives of some of infertile people, professionals, policy makers, the churches, feminist thinkers, and many others. Opinions will be strongly held. Some of these views stem from deep feelings and emotions. While we shall not all agree on everything, we should nevertheless appreciate the feelings and sensitivities of others who hold differing views. There is an integrity about where people stand.

The Warnock report struggled with the difficulty of finding common ground:

> *...it would be idle to pretend that there is not a wide diversity in moral feelings, whether they arise from religious, philosophical or humanist beliefs. What is common... is that people generally want some principles or other to govern the development and use of the new techniques.* (p 2)

1. THE ETHIC OF CARE

The Canadian Royal Commission, when discussing its ethical framework and guiding principles, saw a choice between two overall approaches: one was "*an overarching ethical theory, such as utilitarianism, natural law, or contractarianism*"; the other was "*a broader ethical orientation - called the ethic of care - and, within that orientation, a set of guiding principles to serve as a prism for moral deliberations*" (pp 49-50). The Commission chose the second path and we see great advantages in doing the same. To obtain agreement of a diverse population to a particular theory is very hard and may even be quite inappropriate.

The Royal Commission noted that the ethic of care has developed in both feminist theory and religious thinking. It explained the ethic of care in this way:

> *... the ethic of care holds, broadly speaking, that moral reasoning is not solely, or even primarily, a matter of finding rules to arbitrate between conflicting interests. Rather, moral wisdom and sensitivity consist, in the first instance, in focussing on how our interests are often interdependent. And moral reasoning involves trying to find creative solutions that can remove or reduce conflict, rather than simply subordinating one person's interests to another. The priority, therefore, is on helping human relationships to flourish by seeking to foster the dignity of the individual and the welfare of the community* (p 52).

Obviously, there comes a point in policy formation where a choice has to be made between one policy direction and another. But in the lead up to that choice, we see value in the style which informed the Canadian Royal Commission's recommendations. The Canadians set out eight guiding principles to help implement the ethic of care. There was no particular priority in the ordering of these principles, "*no hierarchy here; no principle automatically trumps any other*" (p 53):

> *Individual autonomy, equality, respect for human life and dignity, protection of the vulnerable, non-commercialization of reproduction, appropriate use of resources, accountability, balancing individual and collective interests.*

2. OUR PRINCIPLES

Against this backdrop, we have endeavoured to extract the basic principles which have guided our own thinking and which we believe are generally acceptable. There are parallels with the Canadian principles but we considered that some different aspects emerged in our national scene. The principles do not always sit perfectly together but this simply reflects the complex nature of ethical decision-making. Some will be more important in one particular context, while others will be more significant for the examination of other issues.We are also mindful that many of the issues involving assisted reproduction and genetic engineering have not yet been articulated and yet are just over the horizon. We cannot anticipate everything. Public policy needs to be based on this reality. Thus any system which regulates assisted reproduction must be sufficiently flexible to meet the demands of the future. Even at the level of our principles there may need to be flexibility to take account of rapid change.

Respect for Human Life and Dignity

In an area of great technological advances, there is a risk that human values will be swamped. Where a choice has to be made between human dignity and scientific endeavour, human dignity must be preserved.

> *The moral evaluation of technological procedures must be by reference to values and norms beyond technology itself. Such norms are ultimately based on what it means to be authentically human* (NZ Catholic Bishops' Conference).

The source of these norms will be a matter of debate. But the wisdom of our own people, the experience of the international community, and the stories that people tell of their own lives should inform the process of determining public policy in the area of ART.

ART involves the very beginnings of life. It raises questions about what it is to be human. It is not easy to find consensus on the moral status to be attached to the human embryo. Some groups would regard the embyro as a human being entitled to the same rights as anybody else. But this is not a universal position. For example, it is not accepted in Islam. Despite the widely differing views of the embryo which we are unable to resolve, we nevertheless see great value in acknowledging that all human tissue has mana. This means that not only the embyro but also gametes should be accorded dignity. From this, it follows that there should be no commercialisation of the use of tissue, ie the sale of human parts, including gametes and embyros, shows a disrespect for the mana of human tissue. Another specific example that follows is that there should be no development of animal/human hybrids.

The dignity of choice is another aspect of this principle. This means allowing people the space as equal human beings to make their own judgments in matters which affect them. Such judgments should be fully informed and part of the information might be the caveats expressed by various people about ART procedures and the risks of dehumanisation. In the end however, human dignity calls for each person, couple or group to take responsibility for making up their own minds. The point is made forcefully by the Auckland Infertility Society Inc:

> *Why is the right of an infertile couple to make an informed choice on whether to attempt treatment questioned by others? Nobody ever questions the right of a fertile couple to have children. Why should they question our rights?...Society must allow couples dignity of choice.*

Autonomy

This principle might also be termed freedom of choice or the right of the individual to decide on the basis of informed consent and, as already noted, is an aspect of human dignity. Autonomy is a fundamental principle in medical ethics and gained a sharper focus after the Cartwright Report. It is explicitly recognised in the New Zealand Bill of Rights Act 1990, which states that a person has a right to refuse to undergo any medical treatment and a right not to be treated or subjected to experimentation without that person's consent. Autonomy is also a fundamental principle in a liberal democratic society.

On the other hand, there are limits to autonomy. As the Canadian Royal Commission puts it "*individual rights can be limited when the aim is to protect important societal interests*" and "*it is also important to recognize that different people's rights overlap, that rights are subject to various limitations, and that rights usually come with responsibilities attached*" (p 61). Thus, autonomy cannot be used to justify actions and policies which are harmful to others or which clash with some other significant principles. For example, the interests of offspring or of women may lead to restrictions on autonomy. Members of many cultures, including Maori, have collective values which may intercept the limits of autonomy and these new limits of autonomy must be negotiated. We accept autonomy in this sense as an important principle. Barriers should not be put in the way of people exercising their free choice unless there are clear and positive reasons for such barriers. Policy should also be developed in such a way as to enhance people's informed decision-making but part of that process should be a recognition that decisions may affect the wider family and others in the community.

The Treaty of Waitangi/ te Tiriti o Waitangi

The Treaty of Waitangi is the founding document of our nation and defines the relationship between Maori and the Crown. From the Treaty, Maori derive certain constitutional rights. Examples of the manifestation of these rights include the right to enrol on the Maori electoral roll and the right to take a claim to the Waitangi Tribunal. It is vital that the development of ART in this country recognises and protects the rights and responsibilities of Treaty partners.

Justice

Assisted reproduction is not merely a health issue. Indeed, it is not so much the technical, medical and scientific problems that require the development of public

policy but rather their social, psychological and ethical implications. Many of the issues are therefore issues of justice rather than health. Justice encompasses such notions as equality (taking account of the interests of all persons equally), non-discrimination (ensuring that specific groups are not disadvantaged by particular policies), and privacy.

We wish to highlight two particular aspects of justice:

(i) protection of the vulnerable, and

(ii) legality.

Protection of the vulnerable - The Canadian Royal Commission noted that vulnerability to exploitation can arise from power imbalances but society "*has a responsibility to ensure that vulnerability is reduced where possible and that those who are vulnerable are not manipulated or controlled by those in positions of power and authority*" (p 55). Those who belong to minority groups, those with disabilities, and children are among those who might be vulnerable. However, in this instance, vulnerability can extend to infertile couples and others who seek ART services.

Legality - In determining public policy in any area, human rights legislation and international standards, such as international covenants and conventions ratified by this country, must provide essential touchstones. To develop policies blatantly in breach of these documents is prima facie unsound and unethical. There are numerous international provisions which could be referred to. We mention just a few.

Article 23.2 of the International Covenant on Civil and Political Rights recognises the "*right of men and women of marriageable age to marry and found a family*". This country has ratified that Covenant and is therefore bound by it. The terms of the Covenant are part of the given setting in which policy in relation to assisted reproduction must be set. What exactly the right means in practical terms is, however, a different matter. The right is a negative right in the sense that governments, subject to certain permissible limits, should not intervene to prevent the founding of a family. If the right is also a positive one (and this is far less clear in international human rights jurisprudence), it could have far reaching implications for public provision of services to infertile persons. It could also have implications for surrogacy and other procedures conducted outside the health system. (See Cook "*New Reproductive Technologies: International Legal Issues and Instruments*", written for the Canadian Royal Commission on New Reproductive Technologies). Any right to found a family must not be seen in proprietary terms. It is not a right to have or own a child, whom many see as a

gift, "*a unique person, equal in dignity to every other person*" (Catholic Bishops' submission).

Other international provisions include Article 12 of the International Covenant on Economic, Social and Cultural Rights, which gives a right to the highest attainable standard of physical and mental health and Article 15 which gives a right to benefit from scientific advancement. Articles 12 and 16 of the United Nations Convention on the Rights of Women give among other things a right to access to family planning, and a right to decide the number and spacing of children. Not least is the United Nations Convention on the Rights of the Child, which requires the welfare of the child to be a primary consideration in laws and policies affecting children.

Within New Zealand, important domestic statutes which set down various human rights standards are the New Zealand Bill of Rights Act 1990, the Human Rights Act 1993 and the Privacy Act 1993.

The Best Interests of the Offspring

The desired outcome of assisted reproduction is an offspring. The offspring has no say in the means of conception and therefore is an especially vulnerable party. Some issues such as knowledge of biological origins impact directly on the offspring once born. Other issues may also be pertinent. Should there be implantation of multiple fertilised eggs (with the possibility of multiple births)? How should donors be chosen? How should embryos (which may or may not be implanted and result in a live birth) be treated? Should people who present as poor potential parents be denied access to ART services? Many issues may need to be viewed with consideration to the needs of future offspring. As in other areas of the law and social policy, the best interests or welfare of the offspring (to be) should be paramount. On the other hand, we must also be realistic about the effectiveness of this principle. As one submission put it, "*to determine the best interests of a child at the embryo stage is impossible*" and in some cases where an embryo has an inherited disease which would result in a significantly diminished quality of life, it could be argued that the best interests are that the pregnancy should be terminated. (Dr Michael Legge)

Right to Know Genetic Origins

Although the right to know genetic origins is an aspect of the best interests of the offspring and flows also from the principles of te Tiriti and justice, we consider it of sufficient importance in Aotearoa/New Zealand that it must be listed as a

separate principle. In some places overseas this principle is not accepted at all, but we believe that the position is different here. Knowledge of whakapapa allows Maori to access constitutional rights and cultural strengths. Pakeha also recognise that biological origins are very important for some people as they discover their own identity.

Accessibility

We heard a number of people commenting on accessibility of ART services. For some this is a question of human rights and discrimination. Where services are available they should prima facie be provided on a basis which is consistent with our anti-discrimination laws. For others, the issue was the affordability of the services. We realise that our society is currently considering issues relating to the core health and disability services which should be funded through the public health system. The range of fertility management services are amongst those being considered. However, where the community accepts that a service ought not to be denied, it should be available on an affordable basis, without accessibility being dependent upon economic status.

Quality Services and Accountability

The Ministry of Health considered that "*safety issues are of paramount concern*". The Ministry defined "*safety*" very broadly to include "*cultural safety, physical and mental health*". Safety, informed consent, respect for culture and many other goals rest in many ways on quality services and high professional standards by doctors, nurses, scientists, counsellors and others engaged in assisted reproduction. Transparent and appropriate procedures for accreditation, quality control, ethical approval, training, record keeping, and accountability are vital. One submission refers to "*the need for accountability, primarily because infertile couples can often be a vulnerable population*" (Daniels).

The highest ethical and moral standards are an essential aspect of the provision of quality services. Both the public and the professionals have an interest to ensure that decision-making procedures lead to clear and consistent rules and guidelines. The State has an overall responsibility for high standards and safety.

A further aspect of the provision of services is the appropriate use of resources. The cost of ART varies with the procedure, as does the benefit of the outcome. Resources are finite and must be used effectively but also fairly.

3. CONCLUSION

These eight principles have guided us as we navigated our way through the issues discussed in this report. As science and human understanding advances, they may need adaptation. Not everybody will agree with them all. Some will feel we have left important aspects out. But we believe we have drawn on threads which are well woven into the ethos of our society as we near the end of the 20th century. ART is different from other areas of policy. Careful nurturing of all the developments - scientific, medical, ethical, psycho-social, legal - is essential and the State has a responsibility which it must not forego. We trust that as the Government settles on a framework for the future, our principles will enable policies to be forged in which the country can have confidence.

CHAPTER 5

REGULATION

1. INTRODUCTION

One of the key aspects of our enquiry has been to consider how ART is currently regulated and whether any changes ought to be made. In summary, the present system is one of a mix of professional self-regulation, consumer forces, health services controls, and general statutory provisions.

Our inquiry has not revealed any abuse of the current system. Indeed, the major service providers have been at pains to operate within ethical guidelines and to listen to developing opinion on ART. We have found very responsible professional attitudes (not just from doctors but also the nurses, scientists, counsellors and all persons involved in ART). Despite this, many submissions called for legislation to control ART, in some instances banning certain procedures and in others calling for the establishment of a statutory licensing body. The providers themselves have felt aspects of the present structure frustrating and favour a clear procedure for determining guidelines.

In considering the issue of regulation of ART, we have taken several factors into account:

(a) Above all, there must be a system in which the public can have confidence. ART is an area of peculiar public interest because of the questions it raises about the beginning of life, what it means to be human, and the mind-bending potentiality of technology. The public has an interest in ensuring that there is proper quality control, accountability, and debate of controversial issues, and that the interests of all parties - offspring, women, men, infertile couples, minority groups, professionals - are protected. Even if the present system contains the necessary safeguards, we think that it is still essential to ask the question whether or not it could be improved to enhance public confidence.

(b) Because of the changing needs and attitudes in ART, any system must be flexible and adaptable.

(c) While legislation has its strengths, it also has its weaknesses. Getting a Bill passed through Parliament can be a slow and unpredictable

process. There is no guarantee that the legislation will end up being what is required in a fast developing area of life. If other ways of ensuring adequate regulation exist, it must be asked why these ways are not used. We note the comments of the Legislation Advisory Committee, which we understand to have been adopted by Government when considering legislation (*Legislative Change: Guidelines on Process and Content*, revised edition, Dec 1991, paras 18 and 19):

> *Practice shows that legislation is proposed and sometimes enacted when it is not needed. This is especially so of legislation conferring powers on Ministers, officials and government bodies. Adequate powers may already exist in the common law (including the prerogative) or elsewhere in the statute book. Experience also indicates that an apparent urgent need for legislation, when seen in a broader perspective, may not really be pressing. Or at least it may be that the proposed legislation can be held until it can be handled with related amendments.*

On the other hand, the Legislation Advisory Committee also states (para 20):

> *The question asked does not relate simply to the legal necessity for the legislation. There may be good reasons of policy for the government to commit itself in the legislation to a particular course of action, for example, by way of a statement of purpose and of the principles on which the action is based. These can serve a useful public purpose.*

2. THE PRESENT SYSTEM

We have discussed the present regulatory structure for ART in an earlier chapter. A brief recapitulation suffices for the purposes of this chapter.

General controls over ART exist through the Ministry of Health and the Health and Disability Services Act 1993 for example, control of medicines by the Therapeutics Division, purchasing agreements with Regional Health Authorities, Public Health Commission, Core Services Committee, outpatient charges, and pharmaceutical charges. General legislation is applicable, dealing with issues such as status, eg Status of Children Amendment Act 1987, Adoption Act 1955, Guardianship Act 1968, Children, Young Persons, and Their Families Act 1989 (including the Commissioner for Children) and quality of service provision to consumers such as the Consumer Guarantees Act 1993 and the forthcoming Health and Disability Commissioner Act. Wider human rights issues are measured by the Treaty of Waitangi, the Privacy Act 1993, the Human Rights Act 1993, the New Zealand Bill of Rights Act 1990, the Human Tissue Act 1964 and international instruments to which New Zealand is bound.

Professional oversight is vital to any area of medicine and health. The Royal New Zealand College of Obstetricians and Gynaecologists is the primary focus for those health professionals specialising in ART but the Medical Council provides an important back-up role for the medical profession as a whole. Disciplinary statutes eg the Medical Practitioners Act 1968, the Nurses Act 1977, and the Medical Auxiliaries Act 1966 provide the overall statutory framework in which the professions operate. As part of their professional obligations, all clinics are accredited through the Australian Reproductive Technologies Accreditation Committee (RTAC), which serves a vital purpose in ensuring that appropriate standards are set at an international level.

Because of criticism of regional, variations and the refusal by some local ethics committees to make decisions, the Interim National Ethics Committee was established in 1993 by the Minister of Health. While at the start of our inquiry this Committee had an uncertain future, it has now been decided that it will continue as a permanent body within the health system. Alongside the National Committee is the Health Research Council, which because of the funding implications is likely to be the body to permit through funding any substantial research initiated in this country. In addition, most clinics have their own ethics and policy committees.

3. REASONS FOR STRUCTURAL CHANGE

Many of the submissions and oral conversations aired dissatisfaction with the present system. This came not just from sideline commentators but also from consumers and providers. In some instances, people considered that developments were too slow while, others thought that they were too fast. Beyond the call for something to be done, the range of options were wide.

Our assessment of what is happening at present does not paint a picture of irresponsibility and abuse. Developments have been restrained and providers have responded to the views of consumers and others who have thought long and hard about the issues of assisted reproduction. There is however a sense in parts of the community that there is potential for abuse and this is fueled by media stories from overseas.

In the light of this, we ask the question, is there a legitimate public interest in the control of ART? Put another way, does the State have a particular obligation to regulate ART services? We believe that the answer to this is clearly yes. The State should certainly aim to promote fundamental values in a democratic society, such as privacy and procreative autonomy. But ART gives rise to very fundamental questions about what it is to be human, and how far we can travel down the path of intervening in natural human processes raises deep metaphysical questions for most people. These are issues for the whole community, and not ones to be left to a section of the

community. The State has an ancient and overriding obligation to protect the interests of children, and the promotion of human rights and justice is the task of the State. These are all poignantly affected by ART.

The question then is whether the State can improve its role in overseeing ART in New Zealand. We see the following as general reasons why some structural change is necessary:

(a) The technological and ethical developments call for a system with an appropriate level of community, scientific and professional input.

(b) To ensure that the public have confidence in the system, there may need to be a separate body clearly identifiable as one dealing with all aspects of ART, with a public profile and accessible to the public. Confusion in the public mind as to who is responsible for handling ART issues needs to be addressed. Such a process should facilitate accountability to the public through the Government.

(c) There is a need for clear decision-making processes. At present, these are dispersed over different bodies. Co-ordination is needed between the disparate bodies.

4. OPTIONS

Given that there is a legitimate State interest, among other things, to protect human rights and justice in the area of ART, the question is how that responsibility is best carried out at this time.

Modified Status Quo - Ethical Approval

The present system could be allowed to run with some small modifications. A key element of the present system is the procedure for ethical approval. Very late in our inquiry we were informed of the future shape of ethics committees, although fine tuning of this shape is still occurring. The continuation of INECART as a reconstituted National Ethics Committee on ART (NECART) appears certain. This committee will be a stand-alone committee, accountable to the Director-General of Health. Applications for ethical approval for new treatments and research in ART are to be made to this committee, but in addition to this appraisal role the committee is also to give advice to the National Advisory Committee on Health and Disability Service Ethics (NACHDSE), which is set up under the Health and Disability Services Act. NACHDSE in turn has a limited statutory function of advising the Minister of Health on "*ethical issues of national significance in relation to such matters as the Minister specifies by notice to the committee*" (section 7, Health and Disability Services Act 1993). The decisions of NECART will be subject to a "*second*

opinion" by NACHDSE or a special committee to be appointed by NACHDSE for that purpose. We understand that by "*second opinion*" is meant something similar to a de novo appeal in this judicial system. After that, an application to the High Court for judicial review might also be possible.

NECART's role is a specialist one. Its primary task is to process specific applications made to it for ethical approval. It has restrictions placed on its relations with the public eg it is required to obtain the approval of the Director-General before making media statements or publishing reports. Its advisory role relates to particular issues which come before it. It is not in a position to prepare general guidelines or foster public debate.

INECART has achieved much in its short history and, to improve its future working, we consider that the following points should be taken into account:

- In general the principles of natural justice should apply to its proceedings, ie applicants should have the opportunity to be heard and to discuss any problems with their application.

- The Committee should give full reasons for declining an application or for making requests for modification to a protocol which are other than routine.

- The membership of the Committee should be carefully chosen and balance maintained with respect to gender, ethnicity professional background etc (this has been a point of criticism with some people to whom we have spoken). Periodic turnover of personnel is advisable.

- Whether all ART applications need to go to the National Committee is doubtful. By its nature the Committee meets less regularly than regional committees and is less accessible. We see no reason why policy guidelines should not be drawn up and then routine applications could be dealt with at a regional level.

- Where the Committee makes a decision in what might be called a "*test case*", the Committee should have the power to make the substance of the decision publicly available as a matter of course without the need for the agreement of the Director-General. Some of these issues are of national importance and should not be hidden from public scrutiny.

Modified Status Quo - Professional Regulation

In any structure for ART, there must continue to be a major place for professional regulation. The evidence we have received suggests that the

current system which relies on professional regulation to a great extent has worked well for the country. In part, this is a combination of the Royal College's requirements and RTAC's willingness and ability to accredit New Zealand clinics and in part on the clinics forward-thinking in the development of practices and policies eg their consent forms, their counselling roles and developments such as openness with respect to donor information. Doubtless, the Cartwright Inquiry and findings have acted as an incentive for the review of professional standards and for greater professional oversight.

We have two areas of doubt for the future however:

- For some time, it has been thought that a New Zealand supplement to the RTAC guidelines is necessary. RTAC is not opposed to this but the task must be done by New Zealanders. While some moves have been made to advance this task (which we do not envisage to be enormous), it has not been completed. We recommend that the Royal College give this priority, in consultation with providers, consumers, public officials and the proposed Council which we discuss later. An allied aspect of this issue is that, while the RTAC guidelines are modified from time to time, New Zealand does not necessarily have direct input into this process. This may also be a matter which the Royal College could take up with RTAC.

- Currently, although all ART providers belong to the Royal College, membership is not obligatory and even for members the Royal College's disciplinary powers are persuasive only. Membership of the Medical Council is mandatory but the Council does not have a formal policy requiring accreditation by ART providers and is limited in the extent to which it can control the activities of specialists. Peer pressure, along with consumer resistance, are undoubtedly powerful forces and will operate in the vast majority of situations. We are concerned however that it is possible for a doctor to operate with impunity outside the current structure and it is also possible for a non-medical person to set up a business as an ART operator eg a DIY insemination agency.

  Some of these points might be covered by the Consumers Code which the proposed Health and Disability Commissioner will be required to prepare. The Code will have to include "*the duties of health care providers and disability services providers to provide services of an appropriate standard*". The Code could insist that providers comply with the professional requirements asked of specialists from time to time by bodies such as the Royal

College. This however would not deal with the non-medical entrepreneur.

An alternative or additional method of dealing with that point is for the revised Medical Practitioners Act, which has been under review for a considerable time, to give the Medical Council the power to create a vocational register on which all doctors who wish to specialise will have to appear. Failure to meet the standards laid down, for example by the Royal College, should be the subject of disciplinary powers vested by the new legislation in the Medical Council. Loss of registration on the vocational register would be an obvious form of penalty, which in turn would mean that the defaulter would not be able to provide ART services. These suggestions have the endorsement of the Medical Council (correspondence to the committee from the Medical Council).

We strongly urge that the Government includes such powers within the new Medical Practitioners Act.

Further, the Medical Practitioners Act should have a clear rule that nobody can practise ART or set up an agency or business to assist ART or carry out various other associated activities such as the freezing of embryos and gametes unless they come within the provisions of the Medical Practitioners Act. Breach of this requirement could be made a criminal offence. The intention of this is not to prevent private individuals from undertaking artificial insemination in the privacy of their own homes (to ban this would be going too far in violating the rights and freedoms of individuals) but to prevent the go-between operating with no professional safeguards.

Regulation by Banning Certain Procedures

A number of overseas jurisdictions ban certain specific procedures because of the great risks which they involve and because of the grave philosophical ambiguities that are raised. If for instance human and animal gametes were successfully mixed, what is the moral and legal character of the creature thus produced? Section 6 of the Victorian Infertility (Medical Procedures) Act 1984 makes cloning and "*a procedure under which the gametes of a man or a woman are fertilized by the gametes of an animal*" criminal offences. Other countries have statutory restrictions on the nature of research on embryos, the length of time embryos may be stored, etc. The Canadian Royal Commission thought that "*there is an urgent need for well-defined boundaries around the use of new reproductive technologies, so that unethical use of knowledge is not permitted*" (p xxvii). The Commissioners recommended legislation prohibiting certain

activities including "*using embryos in research related to cloning, animal/human hybrids, the fertilisation of eggs from female fetuses for implantation, the sale of eggs, sperm, zygotes, or fetal tissues, and the advertising for, paying for, or acting as an intermediary for preconception (surrogacy) arrangements*" (p xxxii). (We deal with surrogacy in a separate chapter and comment no further on it here). Other procedures might need to be considered, including placing a human embryo in an animal, placing an animal embryo in a human, and germ line therapy eg see section 7 of the Western Australian Human Reproductive Technology Act 1991.

Where to draw a statutory boundary line is not easy. Most of the activities listed above are not practised in New Zealand and are unlikely to be in the foreseeable future. Most of them would have to be vetted by ethics committees and would more than likely not survive those processes. Some of them may seem fantastic possibilities to some people. While urgent legislative treatment is hard to justify, Parliament may nevertheless wish to clarify the legal position. We favour Parliamentary action at some point on matters relating to cloning, animal/human hybrids, implantation of human and animal embryos in the opposite species, and rather more importantly the supply of gametes and embryos for valuable consideration (other than a travel allowance which is sometimes paid to sperm donors). These matters breach our principle of respect for human life and dignity. Other matters are generally the subject of widespread debate and as such, statutory prohibitions may be premature and inhibiting of proper debate.

Statutory Licensing Body

A model for the regulation of ART which has found favour overseas has been that of a statutory licensing body. Perhaps the best example is the Human Fertilisation and Embryology Authority in the United Kingdom established under the Human Fertilisation and Embryology Act 1990. Broadly speaking, most assisted reproductive services and research can be undertaken only with a licence from the Authority. The Authority performs other valuable functions such as the production of public discussion papers and the preparation of codes of practice.

Legislation would be necessary for this model to be adopted. The legislation would, among other things, have to set out the procedure for licensing, the nature of licences, the terms and conditions that might be attached to licences, an appeal procedure where applications are declined, and the means by which a licence can be withdrawn. The licensing body would have the advantages of permanence, and parliamentary endorsement and scrutiny.

A statutory licensing body has the support of a number of people who made submissions to us. Providers also see some advantages, in that they would be

operating with an official seal of approval and unlicensed operators would be shut out.

Despite these points, there are very good reasons why, in our opinion, a full scale licensing system is not necessary or even desirable in this country. In summary, the reasons are as follows:

- New Zealand has a very small number of ART service providers. A licensing system for such a small number may amount to using a sledgehammer to crack an egg. Contrast the United Kingdom where there are well over a hundred providers, and the New Zealand situation is put into perspective. There is the possibility of unprofessional operators opening up in New Zealand. But this point can be addressed in the way suggested above under "*Modified Status Quo - professional regulation*".

- A statutory licensing system would duplicate what we already have through the RTAC accreditation procedures. While RTAC is not a statutory or public body, it nevertheless functions to high standards and forces our providers to live up to standards which are not purely locally determined. While there is some criticism of the lack of a New Zealand supplement to the RTAC guidelines, this problem can be addressed, as we have suggested above. Otherwise, there has been no evidence that RTAC cannot serve New Zealand's interests perfectly adequately and to our advantage.

- It may be hard to find appropriate people within New Zealand to perform the necessary inspection functions of a licensing authority without turning to providers themselves or their associates. The pool of knowledge and expertise is very limited in this country and the public interest may be much better served by being part of the more widely based Australian accreditation scheme.

- A licensing body could be very costly to both the taxpayer, the providers and consumers. The taxpayer would have to bear the burden of setting up the infrastructure, but at least some of the cost is likely to be paid for by applicants and in turn passed on in higher fees. Providers already bear the not insubstantial cost of RTAC licensing but that is eased by economy of scale. One of the criticisms we have heard of the United Kingdom Authority is its cost to consumers.

- In summary, there is already a satisfactory and cost-effective system of accreditation for our clinics which can be improved in

a few ways discussed above. A local procedure may be unnecessarily costly, bureaucratic and inflexible. However, the need for a statutory licensing system should be reviewed at 3-5 yearly intervals.

An Advisory and Overseeing Public Body

A Council on Assisted Human Reproduction

We have in mind the establishment of a public body with advisory and overseeing roles. The name we suggest is the Council on Assisted Human Reproduction. In broad terms this Council would be the primary focus for the legitimate public interest in assisted reproduction. It could act as an advisory body to Ministers, and it could prepare or assist in the preparation of codes of practice and guidelines. It would have transparent procedures and be accessible to the community. It would liaise with the variety of different agencies which play a role in the work of ART. It could have a powerful influence on future policy formation, in safeguarding competing interests and in overseeing assisted reproduction generally.

It would fulfil many of the same valuable public relations functions as the United Kingdom Human Fertilisation and Embryology Authority, minus the executive function of licensing. It would fill a vacuum in the present structure.

The Name

We have thought carefully about the name of a new body. The common New Zealand terminology has been "*assisted reproductive technologies*" or ART. We were not entirely happy with this language. We searched for a name which emphasised the human side and down played the technological. There is some unease with language which treats people (especially women) as the objects of scientific and medical intervention, rather than as the subjects of informed self-determination. Respect for human dignity calls for a culture which fosters the latter. The phrase "*assisted human reproduction*" may not be perfect but it captures, we hope, the right tone.

Statutory or Non-Statutory?

It is quite possible for a public body to be established and to function successfully without tailor-made legislation. The Legislation Advisory Committee has expressed the view that special legislation is not needed to establish government departments and may indeed create unnecessary problems *(Departmental Statutes, Report No 4 1989)*. It is quite possible for the

Government, by Cabinet decision, to establish a special purpose body and to set out its functions, terms of reference and membership.

However, there are also attractions in having such a body established by Parliament. Because of the widespread interest in the topic of assisted reproduction, the support of Parliament for the work of a public watchdog and advisory body might give the members of that body a much greater sense of confidence and official backing. A non-statutory organisation may be perceived as having insufficient teeth or be nothing more than a stop-gap measure, even though perceptions may differ from reality.

In the end, the decision whether legislation is desirable for the model under consideration is a political one. We are a little less concerned with the means of achieving the object than with the object itself. However, if the Council is established on a non-statutory basis, its constitutional basis should be reviewed within five years.

Does the Council Differ from the National Ethics Committee?

At one stage, we envisaged the Council having a role borne by some similar bodies overseas of approving research and treatment protocols. This function will now be performed by the permanent National Ethics Committee on Assisted Reproductive Technologies. It could be asked what the Council would do that is not done by NECART. We are clear that the Council will have a number of vital roles making it quite different from NECART, which has a specific brief to process the applications that are made to it. Among other things, the Council will be involved producing and helping in the preparation of codes and guidelines. It will respond to the Government for advice but also be proactive in monitoring developments in New Zealand and overseas. It will have the ability to assist public debate and education by preparing discussion papers and providing other comment on matters of community concern. The overall public watchdog role of the proposed Council is a very different one from NECART.

Functions

The more specific functions of the Council will have to be carefully crafted but they could be along the following lines:

1. To liaise with agencies professionally involved with assisted reproduction and to examine in consultation with those agencies the scope for increased co-ordination.

2. To work with RTAC, the Royal College, the Medical Council and the Council on Health Care Standards to ensure that there are appropriate standards for the accreditation of ART service providers.

3. To respond to requests for guidance made by the National Ethics Committee on Assisted Reproductive Technologies on the ethical issues arising in research projects, new treatments or other aspects of assisted reproduction.

4. To keep itself satisfactorily informed on all matters relating to assisted reproduction, with particular emphasis on new developments, and to advise the Government on the need for any Government action.

5. To respond to requests for advice from the Ministers of Justice and Health.

6. To co-operate with professional groups involved with assisted reproduction, and in consultation, as appropriate, with other agencies (such as the Human Rights Commission and the Privacy Commissioner) and also, where appropriate, after providing the public with the opportunity to make submissions, to develop guidelines or codes of practice relating to assisted reproduction in cases where a guideline or code, or an improved guideline or code, is considered to be necessary, and to consult the Minister of Justice on the terms of any such code or guideline before it is issued.

7. To promote by education and publicity the level of understanding and factual knowledge about assisted reproduction in the wider community.

8. To foster research into the medical, social, psychological, policy, ethical and other aspects of assisted reproduction in co-operation with the Health Research Council, the Foundation for Research, Science and Technology, the universities and other research agencies.

Powers

One question is whether a non-statutory Council would have powers that have legal force. Is there anything, for example, to stop someone totally ignoring the codes of practice which the Council produces? While the answer is probably that there is not, this is not in itself a reason for requiring statutory powers. At present, providers are bound professionally by ethical standards. If they failed to comply with these standards, they would lose their accreditation and along with it, their professional standing and public reputation. It is therefore suggested that there would be irresistible pressure to comply with codes and guidelines issued by the kind of public body under consideration and to co-operate generally with its activities.

If the Council were established by statute, the Council's powers would be expressly spelt out in the statute and be binding in the manner decided by Parliament.

Parliamentary Scrutiny

Because the Council would be funded by public money (we suggest out of votes Justice and Health equally), some Parliamentary scrutiny is justified. An annual report to Parliament could be provided for, or alternatively an annual report to the Ministers of Justice and Health jointly, which they can table in Parliament if they so desire.

Membership

Membership of the Council would have to be appropriately made. The issues are not simply health ones but raise status, psycho-social, and human rights issues, amongst others. We suggest that appointments are made jointly by the Ministers of Justice and Health, after consultation with the Ministers of Women's Affairs and Maori Affairs. Appointments would have to take account of the need for ethnic and gender balance. Membership should include representation from the consumer groups eg the NZ Infertility Society, professional bodies (RNZCOG, counsellors and nurses), the psychological and social science perspective, the ethical and/or theological perspective, and the scientific community. Certain other agencies, such as the Privacy Commissioner and the Human Rights Commission, should be consulted when a relevant issue is before the Council.

Careful consideration also needs to be given to the balance on any Council between experts and officials on one hand and lay participation on the other. A strength of health ethics committees since the Cartwright Report has been lay involvement and the consequential tapping into the community. Any umbrella co-ordinating body dealing with ART must be sensitive to community opinion and the fear is expressed in some quarters that official bodies can be subject to "*expert capture*". However there is also the possibility that community representatives get "*captured*" by particular interest groups which do not really represent the ordinary views of the public. Further, a lot of the work of a Council on Assisted Human Reproduction will call for specialist knowledge and expertise. We emphasis therefore that it is a matter of getting the correct balance of representation on any new Council.

Size

Any Council must be representative but also not be too big. To ensure that the Council can proceed effectively, an optimum size for a Council would be

between five and nine. Size is less of the essence if there are good support services and effective consultation procedures.

Meetings

The Council, while being a part-time committee, should meet regularly but be able to make decisions at other times by means of electronic communication. There should be staffing back-up from within the government sector. An official from either Health or Justice should be designated as the Secretary to the Council.

Cost

We believe that the proposed Council can operate within a relatively modest budget. But, as it will be serving a significant role in representing the public interest, it must be given sufficient resources to carry out its task adequately.

Relationship with Other Organisations and the Community

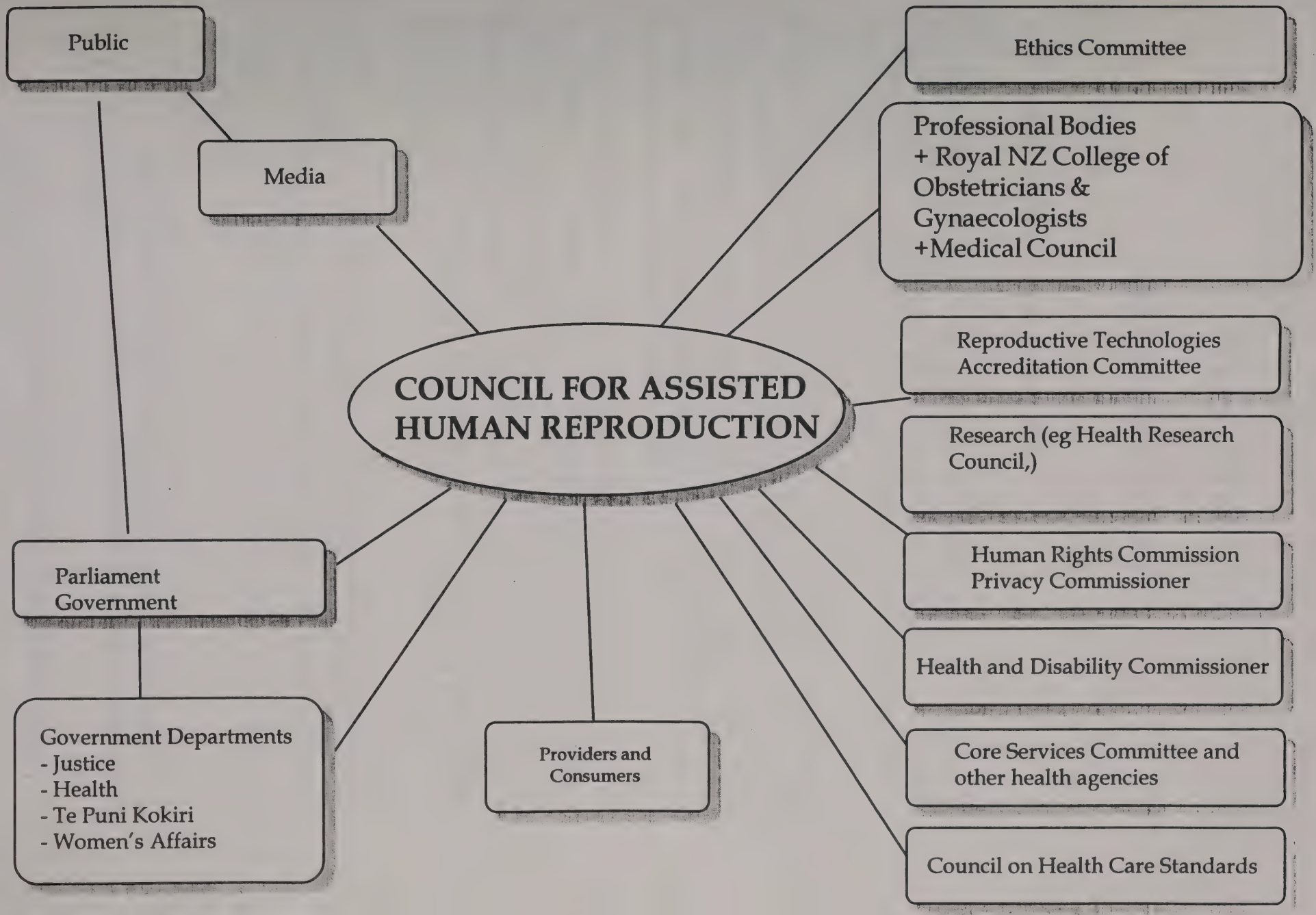
The Council will be charged with the task of liaising and co-operating with various organisations and institutions which play a part in assisted human reproduction. The Council will also be a conduit between these organisations, the community and the Government. The position can be pictured in the accompanying diagram.

5. SUMMARY

In the field of assisted human reproduction, the public is entitled to a system which it can trust. Much of the existing system works well, although it is hidden from the sight of many people in the community. We believe that the time is right for a new piece to be added to the current framework, a piece which will serve the public interest in a practical and flexible way. While we see no need in New Zealand at the present time for a special licensing law, we do see a need for a body such as the one we have detailed in this chapter. The aims for the proposed Council on Assisted Human Reproduction are ambitious but achievable. The Council could be established by statute but this is not strictly necessary. In the interests of getting the Council up and running quickly, there may be advantages in the Government's appointing the body as part of its normal executive function.

We have found that a case for change exists. But we have endeavored to come up with an option which is practical and builds on the foundations already laid. The Council on Assisted Human Reproduction will help us all navigate the waters ahead.

POSSIBLE FUTURE FRAMEWORK



CHAPTER 6

DISCRIMINATION

1 BACKGROUND - HUMAN RIGHTS

Society's values have changed enormously in a very short time. Only a few years ago, legal marriage was the only widely accepted family structure. Divorce was difficult to obtain and frowned upon. Extra-marital sexual relations were regarded as immoral. There was little need for solo parents to have recourse to the State for financial assistance. The State did not interfere in family life.

Today, de facto relationships are common and treated as an acceptable alternative to legal marriage. Divorce and remarriage are a frequent pattern and the State pays large sums in family support. Lesbian and gay relationships are no longer hidden and people understand that the notion of "*family*" is not limited to the traditional "*nuclear family*". Society now frowns on domestic violence, child abuse, smoking and substance abuse, and ecological damage. These values would hardly have been recognised a generation or two ago.

Of pivotal importance in the value shift over the last few decades has been the development of human rights instruments and the campaign against discrimination of various kinds. While this was marked officially in New Zealand with the creation of the office of the Race Relations Conciliator, the passage of the Human Rights Commission Act in 1977 was a staging post for action against discrimination on a much wider basis. The grounds of unlawful discrimination included race, colour, ethnic or national origins, sex, religion, and marital status (which was undefined).

In 1993, the law was completely revised by Parliament and is now found in the Human Rights Act 1993. Important new grounds were added into section 21, including disability, sexual orientation, and family status. Age was added slightly earlier. The same anti-discrimination grounds are found in the New Zealand Bill of Rights Act 1990. To understand the meaning of these grounds, the following points should be noted:

- "*Disability*" includes physical, psychiatric and intellectual disability, and significantly for those with infertility problems "*any other loss or abnormality of psychological, physiological, or anatomical structure or function*".

- "*Sexual orientation*" means heterosexual, homosexual, lesbian or bisexual orientation.

- "*Family status*" caring for children or other dependants, not having any such caring responsibilities, living with someone, being a relative of someone.

- "*Age*" does not apply to young people under the age of 16.

- "*Marital status*" is now defined to cover single, married, married but separated, divorced, widowed people and people living in de facto relationships (possibly including same-sex relationships).

Discrimination in employment and the provision of goods and services, along with housing and education may form the subject of a complaint to the Human Rights Commission and ultimately may end up in the regular judicial system. In addition, the Human Rights Commission has wide powers to comment on human rights, to advise the government and to prepare guidelines. By the end of 1998, the Commission has the responsibility of reporting to the Minister of Justice on any legislation which infringes the spirit and intention of the Human Rights Act. The significance of this is that laws or practices which are inconsistent with the Act should not normally exist.

2. OUR APPROACH

The principles which have guided our report include "*justice*" and as part of that principle we noted that domestic human rights legislation and international instruments are essential touchstones in the development and evaluation of policy. The Human Rights Act must therefore be the basis for any discussion of discrimination in the field of assisted reproduction. It should be applied to any guidelines, ethical decisions or policy advice. To suggest anything different would fly in the face of Parliament's intention in the Human Rights Act last year. It would also run counter to the values shift to which we referred earlier. An overwhelming case would have to be mounted to convince Parliament to back track on the path it set in 1993.

With this in mind, we consulted the Human Rights Commission and sought its advice on the discrimination issues arising in the context of assisted reproduction. We are grateful for the careful submission that the Commission made and which is contained in a publicly available document [appended to this report]. By and large, we have accepted the Commission's statement of the law, although it will become apparent that in some respects we consider that there is room for slightly differing emphases.

We are aware that the effect of the Human Rights Act is regarded as controversial by some sections of the community. Human rights laws are however introduced to bring about change and change is not always easy at first. We therefore welcome debate on these issues but caution against pleas for special exemptions from our

country's human rights standards unless there is societal consensus in favour of such exemptions.

3. CONFLICTING RIGHTS

Rights which favour one section of the community may at the same time deprive another section of the community of other rights. For example, rights for the disabled may have the practical effect of forcing others to take measures to ensure that the disabled can exercise their rights. The Commission recognises that "*few rights are unconditional*" and "*certain situations may require the Commission to find a balance between the rights to non-discriminatory treatment and other competing human rights*" (p 12).

In the field of assisted reproduction there "*are perceived conflicts between the rights of the child and the right to found a f*amily". But the Commission also noted that "*there is little consensus in the community about what constitutes the optimum environment for raising children*". The Family Court, which has long had experience in weighing up the welfare of the child, does not do so by reference to sexual orientation, marital or disability status but rather by looking at each situation and each child on the individual merits. Blanket rules about what is best for children are avoided.

When considering the challenge of the Human Rights Act to assisted reproduction services, simplistic appeal to the welfare of the child will not be an answer. The United Nations Convention on the Rights of the Child, which is one of the United Nations Conventions mentioned by implication in the title of the Human Rights Act, requires the welfare of the child to be a primary consideration, but it cannot be assumed that the welfare of the child is necessarily in conflict with human rights legislation. In some particular cases, the welfare of the child may appear to drive towards a different result from the Human Rights Act. But the apparent conflict could be a matter of initial impression only. Individual cases will need to be examined from time to time to see whether there has indeed been unlawful discrimination and discrimination to protect the child may in the particular circumstances be justified. In other words, discrimination to protect the child may not necessarily fall foul of the Human Rights Act. This however is a very different position from a practice which automatically excludes a sector of the community from access to services. Likewise, denial of services on proper medical grounds will not breach the Act. To be unlawful, discrimination must be on one of the grounds in the Act.

4. HEALTH INSURANCE

Our research indicated that medical insurance companies do not normally cover infertility treatment. This has been the subject of complaint among those making submissions to us and the grievance is exacerbated by the lack of public IVF facilities in many parts of the country. The Human Rights Commission states (p 11):

> *If it is accepted that infertility is a disability, then it would seem that infertile people are being discriminated against as a group by medical insurers.*

As "*disability*" is defined very broadly in the Act, it is hard to exclude infertility from the notion of disability. The Commission says (p 8):

> *Those people who are infertile due to a physiological inability to conceive or bear children (and this would include those women whose health would be severely at risk by carrying a pregnancy to full term) appear to fall squarely within the definition of disability under the Act.*

The Ombudsman has also made an analogous ruling. In *Case No 22991 Post Office Bank Ltd*, the employer was found to have wrongfully refused sick leave to a couple undergoing IVF treatment. The Ombudsman's decision was based in part on the conclusion that infertility is a disease of the reproductive system and that "*the disease of infertility necessitates medical treatment; and that in-vitro fertilisation is one of the appropriate forms of treatment*".

It appears therefore that medical insurers are in breach of the law and should change their practices. The Commission points out that differential treatment can be justified if there is actuarial evidence to support this and that the Commission is pursuing this matter with insurers. Even so, it is hard to see how a total ban on insurance cover can be justified. In our view, insurers have a responsibility to examine their position as a matter of utmost urgency and, no matter what the technical actuarial position is, should now comply with the spirit and intention of the Human Rights Act.

5. DONORS

Clinics regularly discriminate between donors. For example, donors who are HIV positive are not used. Likewise, there is often an attempt to match donors with the couple seeking donor insemination, especially with regard to racial and ethnic factors.

This form of discrimination is not in breach of the Human Rights Act. The explanation for this is that donors are not receiving goods or services from the clinic but rather are making a gift. It appears to us that there are sound reasons for discriminating in the use of donors, primarily in the interests of the offspring. The Human Rights Commission does, however, suggest that guidelines on donor selection may be desirable and we consider that this is a task which could be undertaken by the proposed Council on Assisted Human Reproduction in conjunction with the Commission, possibly using the Commission's powers in section 5 of the Human Rights Act to prepare and publish guidelines.

Another question is whether donors may impose discriminatory conditions on the use of their semen eg that it not be used to assist a lesbian couple and whether

clinics are bound by such conditions. The Commission's view is that donors may impose such conditions without breaching the Act and that clinics will likewise not be in breach "*if those conditions are binding on the provider*". We understand the latter to refer to an agreement between the donor and the clinic on the making of the semen donation (the evidence for this agreement will often be a consent form signed by the donor and any other documentation, although oral conditions might also be binding). Such an agreement is probably a contract in the strict legal sense (both parties are agreeing to do something under the terms of the agreement) and thus the clinic will be bound by any terms.

These points about donors raise two other issues which are of wider significance:

- The range of donors needs to be widened, especially those from minority ethnic groups. This is recognised by the clinics but may require more concerted efforts and public education.

- In the past four to five years, donation practices have changed, most notably in the move away from anonymity. The other side of this coin, often forgotten, is that donors have interests which need to be respected along with everyone else's. Donors are now more likely to want to know what has happened to their semen and whether a child has been born.

6. SEXUAL ORIENTATION

The question of lesbian couples having access to donor insemination services is a live one in this country. While there have been ethics committee decisions to the effect that there is no ethical objection to lesbians being assisted, the real question today is whether they can be denied services simply on the ground of their orientation. Access to services by gay men may be more hypothetical because this necessarily implies some form of surrogacy, but the application of the Human Rights Act to gay men ought otherwise to be the same as for lesbian women.

The view of the Human Rights Commission is quite clear that a refusal to provide services on the grounds that a couple are lesbian is in breach of the Human Rights Act. Arguments for this view can be based on both the "*marital status*" and "*sexual orientation*" grounds of the Act. Some clinics have argued that they offer their services only to people who have some physiological infertility. So, it is argued that, as lesbians' "*infertility*" is social, not physiological, and flows from the nature of their relationship, they fall outside the services being offered. Some have a stated policy that donor insemination treats "*male infertility*", which also focuses on physiological infertility. The difficulty with this argument is that fertility clinics are, to all intents and purposes, offering donor insemination (among other things) to members of the public. To limit these facilities to some members of the public only is almost certainly going to involve a form of discrimination which is outlawed by the Act.

We note the hesitation of some clinics to provide for lesbians. There may be a feeling that the community at large is not ready to contemplate such activities and some providers may have their own religious and ethical beliefs about the matter.

The matter must however be seen in perspective. First, evidence does not suggest that children brought up by lesbian couples will be at any greater risk than children brought up by heterosexuals. (See the Canadian Royal Commission, pp 456-457 for similar propositions: eg "*There is therefore no demonstrated basis for restricting the experience of parenting to heterosexual or married couples for the best interests of the child*"). Secondly, lesbian and gay couples have been bringing up children for many years, often as a result of earlier heterosexual relationships. It is not a new phenomenon. Thirdly, a lesbian couple can become pregnant either by a "*do-it-yourself*" insemination or by natural intercourse with a willing volunteer. The essential reason for using a clinic is to ensure that safe medical procedures to prevent infectious diseases are used and that information is made available, so that the developing offspring will have access to genetic information in future years. Fourthly, the legal system has had no difficulties with the notion of lesbian and gay couples having care of a child. In a very recent landmark decision in Britain, two lesbians were both granted parental responsibility over a child born to one of them, effectively recognising that both were the parents of the child. The decision did not attract a flood of protest. Finally, providers have made choices to work in this area. As all other aspects of the law must be complied with, it is hard to see why human rights laws should be put into a special category.

As the law stands, providers must not discriminate on the grounds of sexual orientation. This does not mean that all lesbians can always demand the services of clinics. The individual circumstances of some couples (indeed of heterosexual couples as well) may justify denying them donor insemination. For example, if one of the partners had a record of child abuse, that might be a reason in the interests of the potential offspring for refusing insemination. As discussed above in our section on conflicting rights, discrimination on this basis is not necessarily in breach of the Human Rights Act.

7. MARITAL STATUS AND SINGLE PARENTS

Discrimination against de facto partners would be in breach of the Human Rights Act but as the clinics now extend their services to de facto couples, the point is academic. Rather more difficult is the case of the single woman who seeks donor insemination. The Commission's view is that refusing to provide for the single woman would breach the Act. The Commission notes:

> *The shift in current legislative and judicial thinking reflects the reality that family composition in New Zealand society is becoming more diverse and single parenthood is becoming increasingly common.*

We are not sure that there has been a legislative and judicial shift towards actively promoting single parenthood. While the existence of the domestic purposes

benefit and the availability of "*easier*" divorce make single parenthood more manageable than in earlier decades, the public policy in this area may simply be a reflection of social reality and a desire to ensure the care of children already born rather than a positive shift in thinking.

There is some evidence to suggest that single parent homes are financially far less secure than two parent homes. A child being born into a single parent home may therefore in some instances be born into an "*at risk*" situation, which may be detrimental to that child. There could therefore be good public policy reasons for not, as a general rule, actively encouraging single parenthood. Where assisted reproduction is used, a child is deliberately being born into a single parent family. This does of course happen frequently by natural intercourse but whether reproductive technologies should be used to assist this is a matter of some controversy.

It is our view that a clinic which has a hard and fast rule that no single person will be helped would be in breach of the Act. However a clinic which wishes to assure itself that the single person is able to provide the proper care for the child and thus wishes to minimise the risk to any subsequent child would not be in breach of the Act if it denied services where there was doubt. Discrimination here, which would have to be on a case by case basis, would be based on the welfare of the child, not on the basis of the marital status of the mother.

Some guidelines for the benefit of clinics may be necessary in this delicate area. These guidelines might be produced by the proposed Council on Assisted Human Reproduction or alternatively, the Human Rights Commission could use its powers under section 5 of the Act to prepare and publish guidelines.

8. DISABILITY

The Commission considers that the clinics cautious approach to providing services to people with disabilities is in breach of the Act. But as the Commission points out "*the question of whether people with disabilities should have access to these technologies must depend on the balancing of various factors which affect those people's capacity to parent children*". In other words, as with single persons, there may be genuine indications in particular cases why services should not be offered to certain people. We endorse the Commission's suggestion that "*procedures for assessing the prospective parent's ability to parent and the children's best interests are recommended in order to prevent unjustifiable discrimination of potential ART recipients*" (p 7).

9. AGE

Some clinics have upper age restrictions on women who will be provided services. In addition, from overseas we know that post-menopausal women are capable of

bearing children with the help of medical intervention. The latter has aroused controversy and some countries have banned such procedures.

The effect of the Human Rights Act appears to be that age restrictions are unlawful. The Commission states:

> *At present it appears that men do not experience discrimination by private providers on this ground, and given that the medical technology exists to make post-menopausal pregnancy relatively safe for mother and child, older women should not be discriminated against.*

We consider that this needs to be qualified by reference to individual cases. Where there are medical indications that an older woman should not bear a child, then a refusal to assist would be justified and not be in breach of the Act. Pregnancy and childbirth are significant metabolic and cardiovascular challenges to one's body. Increasing age often means significantly increased risk and perhaps the increasing likelihood of needing donated ova. We suggest that it is incumbent upon a clinic to make very careful assessments of each case. Refusal based on unacceptably high medical risk would not be in breach of the Act.

The arguments for and against post-menopausal pregnancies are balanced. On the one hand, there are greater risks and some of these risks may be difficult to predict. It may also be undesirable as a matter of public policy to facilitate a situation where children have parents who are many years older than usual, with greater chances for instance of parental death while the child is still dependent. On the other hand, there is nothing to stop older men becoming fathers through natural sexual relations and many children are brought up by grandparents and people of mature years. Furthermore, it could simply be asked why a woman, properly counselled and fully appreciating the implications of the procedure, should not be allowed to make her own decision whether or not to undertake it.

Further public discussion of this issue is merited. The Council for Assisted Human Reproduction should have a responsibility to monitor developments in New Zealand. In the meantime, the Human Rights Act sets the basic ground rules for access to services by older people.

10. RACE

The endeavour to match donors with recipients becomes problematic for particular ethnic groups because of the shortage of donors from certain groups. The Human Rights Commission, while not challenging the general policy of matching, suggests that at the end of the day, if a couple from a particular ethnic background are refused donor insemination because there are no donors from the same background, then they have been discriminated against because of their race. In other words, semen from another racial group should have been offered to the couple, who could then choose whether to proceed. The donor should probably be consulted as part of this process. Likewise, the couple who arrive at a clinic with a

personal donor from a different ethnic group should not be denied services just for that reason.

The question may not however be finally determined. The Commission adds:

> *In determining whether miscegenation by ART is an infringement of individual rights to cultural determination and preservation of national identity, we need to ascertain how ART children will experience the ethnic, racial or national aspects of their genetic origins.*

Further consultation by the Commission with the tangata whenua is taking place on this issue. One matter which needs further thought is the extent to which ART policies should mirror those in adoption. We consider that further consideration should be given to all these issues by both the Commission and the Council on Assisted Human Reproduction.

11. GENUINE JUSTIFICATIONS

Section 97 of the Human Rights Act gives the Complaints Review Tribunal power to declare "*any act, omission, practice, requirement, or condition*" otherwise unlawful to be lawful if there is a "*genuine justification*" for it. This power is not given to the Human Rights Commission itself and it is necessary for an application to be made in each case to the Tribunal. The Commission states:

> *Section 97 can perhaps be seen as a safety net provision to avoid unreasonableness that may be caused by the application to the Human Rights Act without exception.*

As no cases have so far gone to the Tribunal under this provision, it is hard to anticipate how an application by an ART provider would be received and what kind of justification would be a "*genuine*" one within the terms of the Act. This procedure does however offer providers an important avenue of potential redress if they are disturbed by the implications of the Act.

12. APPLICATION TO THE PUBLIC SECTOR

Section 151(2) of the Human Rights Act states that "*nothing in this Act relating to the grounds of prohibited discrimination other than those described in paragraphs (a) to (g) of section 21(1) of this Act shall affect anything done by or on behalf of the Government of New Zealand*". The grounds not covered by this provision are those which existed under the old legislation. On the face of it, this subsection appears to create an anomalous distinction in the application of anti-discrimination laws between the public and private health sectors. We see no reason why a public ART clinic should be placed in any different position from a private one, and this is reflected in the views of the Royal Commission in Canada which has fairly similar human rights laws. As a corollary, policies on core health services should be developed against the backdrop of human rights laws.

While there is also an argument that the public sector may be covered by the anti-discrimination rules in the New Zealand Bill of Rights Act 1990, we consider any doubts are undesirable and should be clarified by amending legislation if necessary.

13. OPTIONS FOR THE FUTURE

Continuation of the Present with Guidelines

The effect of the Human Rights Act on ART providers has now become relatively clear. In some cases, providers will be required to modify their practices in order to fall within the law. As we have pointed out, blanket practices excluding specific groups from access to services will generally be contrary to the law. However individual cases can still be judged on their merits and the welfare of the potential child is a factor which can inform this judgment. How to make these judgments is not easy. It is a delicate and imprecise art. It is for this reason that we believe some wider consultation and the production of guidelines is called for, to ensure that there is a proper balancing of interests within the structure provided for by the Human Rights Act. Both the Human Rights Commission and the Council for Assisted Human Reproduction should play their part in this process.

Amending the Human Rights Act

We acknowledge that some providers and some sections of the public are uneasy about the effect of the Human Rights Act. Some no doubt have moral objections to couples such as lesbians being able to insist on using ART services. Others would object to their being able to use the services provided through the public health system, while being less concerned about what happens in the private sector. This latter point may in part be a comment on priorities for the expenditure of public money. On the other hand, we have also had submissions and heard from people who have objected to the discriminatory practices of the past and query whether there is any real basis other than personal morality for restricting services. There is no consensus on these issues.

A change in the law could be made by Parliament, either by amending the Human Rights Act or by passing special legislation to override the Act. Whether this should be done is ultimately a political decision. We caution however against an over-hasty reaction. The Human Rights Act has only just come into force and we are still in a shakedown period with respect to its implications. Furthermore, the issue of offering services to groups such as lesbians is only a small one at the end of the day. Clinics are unlikely to be flooded by gay and lesbian people seeking their services and for the small number of people affected, special legislation may be hardly justified. The only area where physiologically infertile people may be affected is in the waiting times for public services if the population eligible for public provided ART and donor insemination services grows. Beyond these

points, we repeat our starting principle of "*justice*". Assisted reproduction should prima facie be governed by the domestic and international human rights norms that this country has for general purposes committed itself to. An overwhelming case to depart from these norms has yet to emerge in public debate.

Conscience Clause

The suggestion has been made by some providers that a conscience clause ought to be introduced into the law for those who have moral objections to treating certain sections of the community, eg if a person had genuine religious or moral objections to homosexuality, they could withhold their services. An analogy is drawn with the abortion laws, where a medical practitioner can refuse to advise on abortion on conscience grounds, but has an obligation to refer the patient on to another practitioner. Section 38 of the UK Human Fertilisation and Embryology Act 1990 is also worth noting:

> *(1) No person who has a conscientious objection to participating in any activity governed by this Act shall be under any duty, however arising, to do so.*
>
> *(2) In any legal proceedings the burden of proof of conscientious objection shall rest on the person claiming to rely on it.*

We are not aware that section 38 has been used in the circumstances we are now considering, but in Britain there is no equivalent to our Human Rights Act.

The introduction of a conscience clause is an option which the Government might find worth considering. It could alleviate the concerns of some workers in clinics who never expected that they would find themselves in the present dilemma.

However, there are also reasons for caution with respect to this proposal. It may simply in effect amount to a negation of the Human Rights Act. We have already rehearsed some of the reasons why Parliament should not be invited at this stage to backtrack on its decisions of last year. Why ART as opposed to many other services in the community should be singled out for special exemptions from human rights norms is not easy to establish.

Further, there could be practical difficulties with the operation of a conscience clause. What if one key person in a clinic refuses on conscience grounds to co-operate? That person might effectively prevent the clinic from offering the service, leaving the clinic exposed to a discrimination claim. Again, following the model of the abortion legislation, the patient should be referred on to someone else who would be able to meet the patient's requests. However with so few providers in the ART field in New Zealand, in most places outside Auckland a referral may not be a realistic possibility.

14. SUMMARY

We have suggested that the effect of the Human Rights Act is that ART providers and health insurers may need to review their practices and policies and make alterations to comply with the law. We have cautioned against passing new anti-discrimination laws which separate ART off from other services offered in the community. Finally, we believe that a number of concerns about the ostensible effect of the Human Rights Act can be relieved within the present law, either by showing lawful grounds for discrimination or by seeking an exemption under section 97.

CHAPTER 7

SERVICE PROVISION

INTRODUCTION

Health services for assisting human reproduction, mainly donor insemination, have been available in New Zealand for many decades and IVF has been available for more than the last decade. In light of this history, the questions in service provision are not whether or not ART should be available in New Zealand but what, who, why and how.

Currently, the significant issues pertaining to the provision of services in ART include:

- What services are provided
- Who are the service providers
- What conditions are being treated
- How are those services being funded
- What safety issues are relevant

THE CURRENT PRACTICE

What Services Are Provided

The range of services provided for ART in New Zealand has grown over the years, especially during the last decade. Currently this range is determined by a mixture of consumer demand, available technical and workforce capabilities and appropriate ethical approval.

Ethical approval represents the safety net for consumers and should also reflect the values which we as New Zealanders, hold dear. The process for ethical decision-making in medicine has been the subject of review in recent years. The lessons learnt during this review have included the importance of transparency, accountability and public confidence.

The scope of services has also developed. Greater recognition is given to the crisis that a diagnosis of infertility represents, the personal and intimate nature of the subject and the intrusiveness of many procedures. This has in part led to greater

emphasis on the human aspects of therapy with a team management approach and the incorporation of counselling. Providers realise that ART services do not cure infertility but they may overcome involuntary childlessness. Even when offspring are not achieved, the services provided represent a significant journey that couples travel. Resolution to a childfree status may be a significant health outcome.

Who Are the Service Providers

Two types of providers exist. Firstly large tertiary providers who offer a comprehensive range of ART services often in an interesting mix of public and private provision. Secondly obstetricians and gynaecologists in smaller centres who provide donor insemination.

While providers compete in a business sense, we were impressed by their co-operative efforts.

Service providers are currently regulated by a mixture of general statutory provision, professional self-regulation, health service controls and market forces. These are discussed fully under "*Regulation*".

What Conditions Are Being Treated

As noted earlier, infertility is a diagnostic term used for a group of disorders which have different causes, therapies and outcomes. While a range of treatment options exist, they will have differing usefulness for each disorder. Indeed some authors note that the use of some therapies for certain conditions offer little improvement on doing nothing[1]. Because of this, and despite ART being a rapidly developing area, some commentators raised the idea of promoting early investigation and diagnosis together with the use of standard management protocols.

With increasing technological development, more treatment options are available. However, the introduction of new treatment protocols requires ethical approval.

Consideration must now also be given to the types of infertility treated. Traditionally physiological infertility amongst couples where the woman was a child bearing age was the only type treated. Now, the Human Rights Act insists that we consider the treatment of social infertility among single women and lesbian couples together with physiological infertility in post menopausal women. These issues are discussed in more detail in the chapter on "*Discrimination*".

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[1]Gillet W (1988) "*Management of Infertility : A Changing Perspective*" NZ Med J 102 (868):248-251

How Are Those Services Being Funded

A finite amount of ART services are state funded. The recent health reforms have added a dimension to this provision in that some Regional Health Authorities (RHAs), in their consideration of the health needs of the citizens in their area, have supported the development of local providers rather than the single national provider which operated for many years.

RHAs have acknowledged that ART services continue to be part of New Zealands core health and disability support services. Joint ventures are developing to ensure greater geographical access to ART or access to a greater range of technologies. While we noted that there were differences in the fee structures for many public providers, these related mainly to the history of the establishment of each clinic.

Furthermore we noted in the two public funded clinics which were established prior to the Human Rights Act 1993, policies were used to ensure that the limited service reached those who most needed it and those who would be most likely to benefit. These policies were often framed as guidelines on age, family status etc and will need to be reconsidered in light of the new human rights legislation.

Recent years have also seen the development of private service providers in ART. Many consumers told us about being torn between the need to try for a family and yet finding the cost of access prohibitive. Many had health insurance and were angry that these companies did not support them in this health crisis of infertility.

Our inquiries revealed that only one small non-profit insurer gave some assistance to policy holders who sought fertility services. The Human Rights Commission, in their submission to us, felt that this requires follow-up by them. They note:

> *If it is accepted that infertility is a disability, then it would seem that infertile people are being discriminated against as a group by medical insurers ...*
>
> *The present exclusion of infertility treatment from medical insurance policies reinforces the difficulty in obtaining access to ART for those from less affluent background.*[2]

Submissions to us were mixed as to whether or not ART services should be state funded. Many said yes and these obviously included consumers and providers. Some said no while others still supported an arrangement of state funding for investigation and "*low tech*" management. We have concerns however that this will lead to the relative over utilisation of those options which are state funded. Reinvestment of the same resources may permit couples to access a set amount of "*high tech*" management which may have a better outcome.

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[2]Human Rights Commission (1994) submission of the Human Rights Commission to the Ministerial Committee on Assisted Reproductive Technologies Auckland p.11

Safety Issues

Quantity becomes a safety issue when service providers do not have an adequate turnover to maintain and develop technical skills and professional competency. We heard that some forms of tubal surgery should be considered in this regard.

Quality issues should be safeguarded with accreditation and purchaser-provider contracts. As noted previously in the chapter on "*Regulation*" we believe that the New Zealand consumer still needs protection from providers who have failed to achieve accreditation.

Cultural safety was reflected in those submissions who promoted the need for services operating in New Zealand to recognise the concerns, values and culture of New Zealanders including Maori. As noted in the chapter on "*Regulation*" we feel cultural safety could be better addressed if New Zealand guidelines were formally developed and appended to RTAC accreditation of New Zealand providers.

Ethical safety was valued by many who made submissions to us. The process of how decisions are made about the parameters of ART in New Zealand and by whom, was an important prerequisite for public confidence.

Research and development is an integral part of any developing technology. The Canadian Royal Commission noted that it is difficult for a country to absolve itself of the responsibilities associated with research and development without taking advantage of research being done elsewhere. They termed this process "*ethical dumping*".

We note that research on the technical aspects of ART seem to be prioritised over attempts to measure the influence of policy decisions on the physical, psychological, sociological and cultural well-being of offspring. The issue is dealt with further in the chapter on "*Research*".

Comprehensiveness relates to the different elements within the health service working together. The management of infertility relies on general practitioners enquiring about infertility, investigating it where appropriate and referring where necessary. Further, it requires secondary providers to review the diagnosis and investigate further if appropriate, review management options and refer if necessary.

One submission noted that some of the pain of infertility came from uncertainty which was compounded by long drawn out investigations and procedures.

THE FUTURE

While many issues surface in this discussion on service provision, most are dealt with in some detail in other chapters of this report. However we feel two issues require further attention in this section.

Counselling

We received mixed responses in submissions about whether or not counselling should be mandatory. Furthermore it was clear that people had a variety of understanding about what counselling meant.

We noted four types of counselling in the Manatu Maori submission to IMCART.

(i) Implications counselling : this aims to enable the person/couple concerned to understand the implications of the proposed course of action for herself or himself, for their respective families and for any children that may be born as a result of ART;

(ii) Support counselling : this aims to give emotional support at times of particular stress;

(iii) Therapeutic counselling : this aims to help people understand and cope with the consequences of infertility and treatment, and to help them to resolve the problems which these may cause; and

(iv) Cultural counselling : this aims to enable Maori to understand the implications of ART for whakapapa and to explore other cultural options as viable treatments for infertility. Provisions should also be made for whanau counselling when required.

However, it is obvious that there are areas of overlap. For instance, counselling for openness in a couple considering donor insemination might include all of the types listed above.

We recognise that counselling in ART will require specialised training and experience. Training providers in the counselling area should note these needs and develop appropriate programmes so that within a few years, training in this area is managed to minimum standards.

We believe that "*implications counselling*" is a necessary service to achieve informed consent and should therefore be provided to all clients. Furthermore, support, therapeutic and cultural counselling should be provided when appropriate.

ART in Core Health and Disability Services

Many consumers who made submissions to us felt that, after years of contribution to New Zealand society and our public health system, they were unable to enjoy many of the benefits because of their infertility. They had a sense of entitlement to some levels of support in return from the health sector.

The Core Health and Disability Services Committee told us that they were philosophically moving away from the concept of entitlement towards the notion

of benefit. However benefit is not an easy concept to measure. If the benefit of ART is viewed in terms of the likelihood of achieving offspring, then these technologies may be seen as having varying chances of achieving benefit depending on the specific diagnosis.

However, infertile couples told us that they had a strong need to feel that they had done everything possible to have a child. They demonstrated how deeply infertility affected their lives and future. We believe that infertility has a morbidity associated with it for many people and that while it may not be life threatening, it requires attention in a caring society. Many therapies in our health system do not attempt to save lives. Many relieve pain, suffering and the effects of disability to improve quality of life. Joint replacements are a good example. We believe the benefit of ART should be seen in the same light.

Benefit is derived not only for the couple and their family, but also for society. The public provision of ART services provides a training ground for service providers and we feel that this is a legitimate role for the state. Furthermore, as noted elsewhere, the infertile are to some extent a vulnerable population and as a consumer told us:

> *the public system is necessary to help keep the private system honest*[3]

The Core Services Committee, in a letter to us wrote:

> *The Core Services Committee, based on wide consultation, supports an inclusive notion of benefit. Benefit should include more than health status, for example it should also include aspects of wellbeing, to the individual, family/whanau, and community.*

It noted further that much of their work in years to come "*will be to advise more precisely on what types of 'benefit' are appropriate to consider for publicly funded health and disability support services*".

OPTIONS

There are three broad options for the funding of infertility services.

No Public Funding For Infertility Services

We do not support the withdrawal of public funding from infertility services as we believe this would contradict notions of justice for a sizeable minority in our community. It would particularly affect less affluent members of our society which again raises issues of justice. We have considered that the state has a legitimate interest in ART, and some would consider that this included involvement in funding service provision and training of specialists.

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[3]Member NZ Infertility Society 1993 - personal communication Auckland.

Substantially Increased Public Funding For Infertility Services

There is merit in increasing public funding in order to improve access and choices for infertile couples. Barriers from cost of travel, drugs and extensive waiting lists may be overcome with additional resources and equity of access improved. Furthermore the range of services may be broadened. However, we recognise the fiscal challenges that the health sector currently faces and that this option prejudges the debate about core services in New Zealand.

Modified Status Quo For Funding Infertility Services

A modified status quo arrangement would be based on three main factors. Firstly, that the Human Rights Commission follows up issues with health insurers to ensure they are not operating in breach of the Human Rights Act 1993. Secondly that resources are not inappropriately utilised at the secondary level because they can be state funded by development of standard management protocols when the diagnosis is uncomplicated. Thirdly, by the government reviewing the extent to which pharmaceuticals are funded in this area.

We believe that this modified approach is an appropriate interim measure until such time as the Core Services Committee reports.

SUMMARY

We have found that the current provision of services has much in its favour. It fosters a range of providers ensuring some consumer choice. This has to date led to a co-operative provider environment. We believe this environment would be enhanced if health insurers were to become funders for their members. We note that in the new health environment there is nothing to stop enterprising Crown Health Enterprises or RHAs to enter into joint ventures.

We await the Core Services Committee advice on aspects of "*benefit*". We would advise against funding decisions which disrupt the flow of services and referrals from primary to secondary and to tertiary.

CHAPTER 8

INFORMATION - TOWARDS OPENNESS

1. INTRODUCTION

Access to information about one's genetic origins and birth has been a controversial issue. In the past in New Zealand and still frequently in other parts of the world, an aura of secrecy has surrounded anything to do with ART, especially where there have been donated gametes. Attitudes have been changing rapidly in New Zealand and this enables future directions to be surveyed rather more positively.

The main issues are:

- To what extent should children born as a result of donated gametes be able to discover their genetic origins?
- What information is it appropriate for them to learn about themselves - identifying or non-identifying information?
- Should there be any age restrictions on access to such information?
- Should other members of the child's family or whanau be entitled to access?
- Should the donor be entitled to information about any child born as a result of the donation?
- Should any rules be retrospective in effect, ie should rules apply to donors and children born at a time when anonymity was the norm?

The most frequent context in which these issues arise is donor insemination and this chapter will concentrate on that situation. However, it must be underlined that the issues can be just as acute where there has been ova or embryo donation, or where surrogacy is surrounded in secrecy.

2. THE CURRENT PRACTICE

Most but not all of the country's IVF clinics practise a policy of advising donors and recipient parents to adopt openness about genetic origins. This represents a dramatic turnaround from only a few years ago. Several reasons can be proffered to explain this. First, the Status of Children Amendment Act 1987 removed any legal liability from the donor. Thus, an open approach is not going to lead to paternity suits (for males), child support obligations and succession claims. Secondly, the Adult Adoption Information Act 1985 altered the law on obtaining information about adoption. Whereas secrecy had prevailed in the past, the new approach allows birth parents and adoptive children (when reaching adulthood) to approach one another. Analogies were drawn between adoption and ART. Thirdly, the service providers were amenable to new ideas and the system was sufficiently flexible that changes in practice could be implemented without much difficulty. Fourthly and of great significance has been the reawakening of Maori culture and its effect on New Zealand society. For Maori, knowledge of whakapapa is vital for personhood. Secrecy about genetic origins is antithetical to Maori values and could be said to conflict with the principles of the Treaty of Waitangi.

Attitudes appear to be changing rapidly. Caldwell and Daniels[1] cite a New Zealand study in 1985 in which 41% of couples entering DI programmes thought that children should not be told of their origins and only 21% thought that they should. This they contrasted with a 1991 study which showed that 82% of couples in a particular programme thought that they would tell their children about their origins. The New Zealand Infertility Society, which is the national body representing consumers and people with infertility difficulties, recommends that "*only donors who are willing to be identifiable should be recruited*"[2] and their policies in favour of openness have doubtless influenced the practices of clinics.

The RTAC guidelines contain several provisions relevant to the questions under discussion (Guideline 4.4):

> *Gametes or embryos of different parental origin should never be mixed so as to confuse the biological parentage of the conceptus.*

In the past there was a practice of mixing donated semen with the husband's semen, partly on the off-chance that the husband's semen might be responsible for fertilisation but really to prevent identification of the donor.

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1 "*Assisted Reproduction and the Law Implications for Social Policy*" in Henaghan and Atkin Family Law Policy in New Zealand (OUP, 1992). For fuller discussion of other studies see Daniels and Taylor "*Secrecy and Openness in Donor Insemination*" (1993) 12 Politics and the Life Sciences 155

2 Taken from the Society's "*Policy on Information Keeping Where There are Donor Gametes*" (September 1993)

Semen from several donors could also be mixed. These practices are now regarded as quite unacceptable. The RTAC guidelines also require the keeping of records (Guideline 5.1):

> *A permanent record must be kept of all procedures, identifying the patients, donors and recipients of all gametes involved in fertilisation and embryo formation; the final outcome of any attempted fertilisation; the final locations of any conceptions formed by IVF pregnancies.*

Past practices were extremely slack with respect to record keeping, even for purely medical purposes such as tracking possible genetic disabilities in the donor which may have been passed to the child. Many DI children will never be able to know anything about their genetic origins because of the lack of records. The RTAC guideline means that records are now kept and some long term follow-up of children born as a result of assisted reproduction can over time occur.

Individuals may of course engage in do-it-yourself DI, which may be by means of simple implements or even by natural intercourse. There is no way of knowing how much of this occurs, but there are risks, besides the lack of records and public or professional oversight. It is now common practice for clinics to freeze donated semen for six months during which time the donor is tested for such things as HIV and hepatitis.[3] This is unlikely to happen when individuals (or even the well-meaning GP) do insemination themselves, and thus there are risks of passing on infectious diseases and other conditions. The primary concern in this chapter however is that informal DI or DI by unaccredited health professionals will be outside the RTAC guidelines and any other codes of practice that may be developed.

3. CURRENT LEGAL POSITION

Until recently it was assumed that the practice of anonymity was legally enforceable and those involved in donation could not have access to information about the donor or child, as the case may be. Recent changes in the law, most notably the passage of the Official Information Act 1982 and the Privacy Act 1993, cast doubt upon this statement of the law. The Official Information Act covers only information held by public sector providers (although no application has ever been made to test the implications of that Act in the context of ART). The Privacy Act covers both public and private providers. Further changes, including proposed health regulations, will raise more doubts about the legality of refusing access to information. At best, the state of the law can be described as doubtful. The following sections explore the current legal position.

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[3]The RTAC guidelines oppose the use of fresh semen

Under the authority of the Privacy Act, the Privacy Commissioner has released the Health Information Privacy Code 1994. It is likely that identifying donor information comes under the rules of the Code, although other information may come directly under the principles of the Privacy Act. Most of the following discussion relates to the Code, but reference to the Act itself is also necessary.

"*Health Information*"

Information about donation is probably "*health information*" as defined in the Health Information Privacy Code 1994 and section 22B of the Health Act 1956. Information provided in connection with the donation of any body part or bodily substance will be health information about the donor. The fact that a child was born as a result of a DI procedure will mean that that information is health information about the child because it is part of the child's "*medical history*" (see clause 4(1)(a) of the Health Information Privacy Code). A little more controversially, the identity of the donor (ie the child's genetic parent) is also health information about the child, falling under clause 4(1)(e) of the Code: "*Information about that individual which is collected before or in the course of, and incidental to, the provision of any health service or disability service to that individual*". There is no reason why the same piece of information cannot be information about more than one person. This would mirror the approach of the Ombudsman who, in investigating the allied question of information about an adopted person's birth parents, has treated such information as "*personal information*" about the adopted person for the purposes of the Official Information Act 1982. Most people, and most certainly in the Maori community, would regard knowledge of biological origins and whakapapa as being basic information about an individual and it is hard to see how this will not involve the identity of genetic parents.

Non-identifying Information

The focus of debate is on the question of information which identifies who the donor is, or, as the case may be, who the offspring is. Much other information, such as the donor's medical history, may be of interest to the offspring and the offspring's family. Such information, so long as it does not identify the donor, should not create any difficulties under the Privacy Act or the Code. Rule 11 permits disclosure of such information if the use being made of it was one of the purposes for which the information was collected, or if the information "*is to be used in a form in which the individual concerned is not identified*".

Access to Information

Under Rule 6, the individual concerned is entitled:

(1) To obtain confirmation from the clinic that the clinic holds health information about that person, and

(2) To have access to that information.

Prima facie, a donor ought to be able to obtain information about an offspring born as a result of donation, and an offspring (of any age) ought to be able to obtain information about the donor.

The Rule applies to information collected before the date of the promulgation of the Code, as well as subsequently collected information.

Reasons for Refusing Access to Personal or Health Information

Rule 6 is subject to a range of exceptions set out Part IV of the Privacy Act. Three of these exceptions could apply to ART donations.

- Under s 29(1)(c) information may be withheld if it "*would be likely to prejudice the physical or mental health of that individual*". It is suggested that the instances of this are likely to be extremely rare. Indeed the reverse is the more likely scenario.

- Under s 29(1)(d), information may be withheld from a person under the age of 16 if disclosure "*would be contrary to that individual's interests*". This raises the question of whether there is an age when a child should be informed about its genetic origins. Comparisons can be made with adoption. An analogy with the Adult Adoption Information Act 1985 is not very helpful because the ability to access information under that Act does not arise until the age of 20. On the other hand, the experience with open adoption is that a child is now brought up from an early age with the knowledge of the adoption and often there will be a continuing relationship with the birth parents. This suggests that it will be infrequent that age will be a legitimate excuse for withholding health information about a person's birth.

- The most significant reason for refusing a request for information is found in s 29(1)(a):

> *The disclosure of the information would involve the unwarranted disclosure of the affairs of another individual or of a deceased individual.*

Disclosure to a child of information about donation will almost certainly involve a disclosure of information about the donor and the question is whether the disclosure is "*unwarranted*". Where the information is of an identifying kind and it was agreed at the time of the donation that the donor could be identified, then disclosure will not be "*unwarranted*". Likewise, if the donor subsequently waives any right to anonymity, here would be little basis for a clinic to refuse access to the information.

The difficult case is where the donor donated with a promise of anonymity. On the one hand, the donor might be caused considerable anxiety by the unexpected contact with the child and consider that there has been a gross violation of the donor's private life and earlier act of generosity. On the other hand, does this outweigh the interest a person has in knowing their true genetic origins? The child after all had no choice in the matter and can hardly be accused of abusing a system which placed the child in the current dilemma. Furthermore, since the passage of the Status of Children Amendment Act 1987, the donor will not face legal liability for the child. The consequences of the disclosure will be emotional rather than legal and financial.

It is suggested that, on weighing up the conflicting points of view, it is not possible to draw a general conclusion that disclosure of the identity of an "*anonymous*" donor will always be "*unwarranted*". It may be that each case will have to be looked at on its merits to see whether there is any particular factor which renders the disclosure "*unwarranted*".

Consequences - If Donor Information is Covered by the Privacy Act and the Code

A breach of the Code may form the basis of a complaint. Clause 8 of the Health Information Privacy Code requires all health agencies to designate a person or persons to deal with complaints about the breach of the Code. Most complaints should therefore be dealt with at this level. Complaints may also be made directly to the Privacy Commissioner, including where there has been a refusal to disclose health information in response to a request (section 22F(4), Health Act). In the instance of the refusal to supply information, the Privacy Commissioner must be satisfied that "*there is no proper basis for*" the decision to refuse to disclose.

The Privacy Commissioner will investigate complaints and may refer them to the Proceedings Commissioner appointed under the human rights legislation, who in turn may decide to take the case to the Complaints Review Tribunal. The Tribunal has power to grant declarations that there has been an interference with privacy, an order restraining such interference, damages, an order requiring remedial action to be taken, and "*such other relief as the*

Tribunal thinks fit". Breaches of some principles (including principle 11) will follow a different course if they occur prior to 1 July 1996. The Commissioner is empowered to make recommendations to the agency concerned (section 79).

Outside the complaints procedure, the privacy principles and codes do not generally confer any legal rights which are enforceable in a court of law. However section 11 of the Privacy Act creates an important exception in relation to access to personal information (sub-clause (1) of Principle 6) so long as the information is held by "*a public sector agency*". The latter phrase is defined broadly in section 2(1) and will include a Crown Health Enterprise and possibly health sector ethics committees. This could lead to the somewhat anomalous result that a public sector provider of ART services might be suitable in the courts for failure to give access, whereas a private clinic would not be. Whether this applies to "*health information*" under the Code is doubtful, as section 53, which treats breach of a code the same as breach of one of the Privacy Principles, does not appear to extend to section 11.

In summary, significant sanctions are in place for failure to comply with the Code.

Duty to Record Information

There is no legal obligation to record information about the source of gametes. There is however an effective incentive to do so, because, as mentioned above, this is required under the RTAC guidelines, which must be complied with for a clinic to be accredited. Furthermore, practices such as the six month quarantine of semen make recording a practical necessity. The area of concern is where unaccredited health professionals or non-medical people engage in donor insemination and fail to record vital information. This is also an aspect of the debate about surrogacy (which we discuss in a separate chapter).

What information ought to be collected is uncertain. Under Rule 1 of the Code, a clinic should collect information for a lawful purpose connected with a function or activity of the clinic and only to the extent that it is "*necessary for that purpose*". Given the speed with which attitudes to information about donors have already changed within a short space of time, it is not easy to determine what is "*necessary*" as opposed to being "*convenient*" or of possible future use.

Source of Information

Under Rule 2 of the Code, the collecting agency (the clinic) must collect health information directly from the individual concerned. There are exceptions to

this, including where "*compliance is not reasonably practicable in the circumstances of the particular case*". The relevant information for our purposes is of two kinds:

(1) details of the donor of a gamete, and

(2) details of the use of the gamete and any child born as a result. Information of a third kind, ie information about the person or persons who sought an ART procedure to overcome infertility, may also be relevant but is less likely to be sought.

Assuming that biological parentage can be "*health information*" about both the donor and the child, it is not practicable that all the information be collected from the individual concerned. The reason for this is, for example, that genetic information about the child will have to have been collected from the donor. The exception to Rule 2 ought therefore to apply.

Comment on the Present Law

While the current legal position on access to information is open to some debate, the Privacy Act may nevertheless have changed the ground rules quite dramatically for the private sector. This may have happened earlier for the public sector clinics with the Official Information Act. This may be contrasted with the changes made in 1985 to access to adoption information. These changes were made after lengthy public debate and the new system was brought in slowly. The 1985 Act involves a balancing of the interests of the parties and the provision of counselling. Something similar might be desirable for ART.

4. THE FUTURE

A constant theme running through the submissions made to us and in our discussions with people was the desirability for offspring born as a result of donation to have access to information about their genetic origins. The "*right to know genetic origins*" has become one of our guiding principles in preparing this report, but other principles, particularly the Treaty of Waitangi, justice and the best interests of the offspring, point in the same direction.

For some, a principle of openness will come as a surprise, and it will certainly be coolly received in some other parts of the world. But those who have thought their way through the issues and drawn on the New Zealand experience see it differently. We believe that this is an area where New Zealand must work out its own solutions and, if need be, lead the world.

Submissions

A wide range of people and organisations who made submissions supported a policy of openness, and this was particularly evident in the submissions from Government departments. The Department of Social Welfare stated:

> *There is now general agreement amongst the parties involved in ART (including social parents) that children born as a result of donated material have a right to know their genetic identity/whakapapa. The Department's experience in adoption and adult adoption information confirms this view.*

The National Council of Women reported the following:

> *The majority of our members consider that the off-spring of ART have a right to know their genetic origins (including ova and sperm), and that it is extremely urgent to develop a formal centralised system for data collection, storage and access.*

Te Puni Kokiri drew our attention to the Manatu Maori Working Group's Statements in 1991, including the statement "*that all children conceived and born as a result of ART have an inalienable right to full knowledge of their culture and identity*", while the Ministry of Women's Affairs recommended that "*a national policy be developed that ensures that there will be full permanent records and access to information by DI children*". The New Zealand Infertility Society's policy on information keeping "*recommends that only donors who are willing to be identifiable be recruited*" and that there be "*a confidential central registry containing a record of any conception arising from the use of donor gametes and the source of that donation*", including identifying information "*which any clinic would release with the donor's permission when requested by a child or parents on behalf of the child*".

Dr Ian Hassall, the Commissioner for Children, added a further angle:

> *My preference for disclosure does not stand outside of a context of time and place. What might in times past have been commonly regarded by all parties including the child and the adult she becomes as a wholly beneficial conferral of identity, name, place in the world and heritage is in present times more likely to be regarded as reprehensible official deception. Even if in individual cases secrecy can be maintained forever, the knowledge that such secrecy is officially sanctioned will lead many to fear or suspect that their origins are not what they seem and be unsettled as a result.*

A due cautionary note is however entered by IVF Otago:

> *I have a concern that if it is made compulsory for donors to be subsequently identified by the offspring in later years, that in this more conservative part of New Zealand, there would be extreme difficulty enlisting donors.*

Arguments For and Against Openness

The value of openness versus secrecy in donation is obviously a matter that divides people. The Canadian Royal Commission recognised the pros and cons of secrecy (p 464):

> *Secrecy is preferred because it seems to solve so many problems: the man's infertility is hidden, an image of normalcy is maintained, children do not grow up feeling different from their peers, and any potential legal tangles are avoided. In addition, keeping it a secret sidesteps the issue of acknowledging a division between social and biological parenthood for these couples.*

But then, the Commissioners also stated (p 464-465):

> *Commission research showed that maintaining secrecy about the means of conception can be contrary to the best interests of the child...Adults born through DI reported that the decision to keep DI a secret was very damaging - they felt deceived and said they had always sensed that something was "wrong" in the family. Some told the Commission that they found out about the method of conception at a time of family crisis, such as divorce or death in the family - a time when secrets are difficult to keep. Discovering the truth in this way is doubly traumatic; the shock of discovery during an already stressful period is coupled with the realization that your parents had lied to you all your life.*

The Commissioners however decided that "*[u]ltimately, the decision about whether and whom to tell should be made by the parents, as it is rooted in personal values and beliefs*". They recommended that complete records on donation be kept and that information on donors and recipients be accessible to those authorised by a court of law in the case of medical necessity (p 474). They also wanted to ensure that "*the needs of DI families and donors are balanced with regard to access to information about each other*". The Commissioners' position here is somewhat vague and cautious - in the light of earlier discussion in the report, it probably favours the release of non-identifying information but is hesitant about anything more.

The Canadian approach is reflected in legislation already passed in Britain and Australia. Under the Human Fertilisation and Embryology Act 1990 (UK), a person aged 18 or more can find out from the Authority established under that Act whether he or she is a DI child and non-identifying information can be made available after the applicant has been given a suitable opportunity to receive proper counselling. There is power for regulations to be made covering identifying information but only in relation to children born after the making of the regulations. There are no present moves to make such regulations. In Victoria, the Infertility (Medical

Procedures) Act 1984 imposes an obligation on hospitals to keep records and the Health Commission maintains a central register of information about donors and children born as a result of reproductive procedures. A DI child may apply to the Health Commission for the information which it holds so long as it is not information from which a donor can be identified (sections 19-23). Disclosure of information other than in accordance with the Act is an offence. In South Australia, disclosure of a donor's identity can be done only in the administration of the Act, in order to carry out "*an artificial fertilization procedure*", or where the donor consents in the prescribed manner(section 18, Reproductive Technology Act 1988). The Western Australian law is very similar except that the Reproductive Technology Council can issue and amend a Code of Practice from time to time which could include rules about the release of identifying information (Sections 46 and 49, Human Reproductive Technology Act 1991).

In discussing secrecy, the Canadian Royal Commission drew an analogy with adoption (p 468):

> *Although adoptive and DI children are different, the experience of adoptees can suggest what DI children need with regard to access to information about their social and genetic background. Many adoptees who have little or no information about their origins feel as if their life stories "began at chapter two". These adoptees may develop an incomplete sense of identity and may make the search for their biological roots a primary life focus.*

The analogy with adoption may need to be treated cautiously. One writer[4] has argued that it is "*case of 'mistaken identity'*" and gives several reasons for this point of view: DI involves the creation of a child for the purposes of founding a family "*and not the abandonment or neglect of a child leading to giving the child up for adoption*", in DI there is no physical or emotional relationship between the donor and the recipient[5], in DI the mother contributes her genetic material and the pregnancy and birth is a process shared with her partner, and "*the child born of artificial insemination has a real, present, and intentional father/mother...Anonymity is not the protection of an 'ideal family', but of a real one*". But Daniels and Taylor, in an article which has been described as "*a landmark in the North American debate in these issues*"[6], while recognising the differences between adoption and DI, conclude:[7]

> *...what has happened in the field of adoption does have implications for DI. In both practices, several parties with conflicting needs and interests are involved. Those dealing with adoption in the past attempted to resolve such*

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[4]Bartha Maria Knoppers "*Donor Insemination: children as In Concreto or In Abstracto Subject of Rights*" *(1993) 12 Politics and the Life Sciences 182-185*

[5]This of course is the usual case but need not always be the case, as consumers may in some instances bring their own donor

[6]Rona Achilles "*Protection from What The Secret Life of Donor Insemination*" (1993) 12 Politics and the Life Sciences 171

[7]Above n 1,159

conflicts by denying the rights and needs of one of the parties - the child - in order to protect the rights and needs of the other parties - the relinquishing mother and, most importantly, the adoptive parents. It is obvious that this is what is occurring in donor imsemination today: the child's needs and rights are being overlooked in order to protect the couple and the donor.

Daniels and Taylor advance a number of positive reasons why they favour openness in DI. In summary these are as follows:[8]

- **The rights of the child** Drawing on the adoption analogy, the authors note that lack of genealogical knowledge may cause serious psychological problems, but even so "*is it fair to deprive a DI child of information that other children assume is theirs by right? Is it fair to deny that child, and future adult, the right to know the truth concerning such a fundamental issue as her/his genetic background?*"

- **Openness and family relationships** Openness will avoid the pressure involved in keeping donation a secret and the trauma if it is unexpectedly disclosed. It may be beneficial to the couple because by talking about the husband's infertility they are more likely to obtain support.

- **Openness and the community** There is a fear of negative reactions in the rest of the community when DI and infertility are mentioned. However studies suggest that this fear might be largely unfounded, while at the same time secrecy hinders the dissemination of information to the community. Lack of information can often go hand in hand with prejudice.

- **Openness and the donor** It is often assumed that secrecy will protect the donor. However, studies particularly in Australia and New Zealand indicate that donors may not be averse to their identity being revealed. In Sweden, where the law requires identifying information to be available for DI children, there was an initial drop-off in the number in donors but the number is rising again[9].

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[8]Ibid 159-164

[9] Daniels implies that the drop-off may have been largely because of the attitudes of professionals who were unsympathetic to the law change and who tended to refer couples to adjoining countries (eg Norway where the law enshrines the principle of anonymity) which did not have the same information laws: ibid 163. Austria has recently passed a law similar to Sweden's, requiring donors to consent to a child requesting identifying information from the age of 14: see Morgan and Bernat "*The Reproductive Waltz: the Austrian Act on Procreative Medicine 1992*" [1992] Journal of Social Welfare and Family Law 420.

> *The above studies, and the Swedish experience, present major challenges to accepted views regarding donors' attitudes. Donors, it appears, are not dispassionate males whose main interest is the payment they might receive for donating. The results of these studies suggest that some donors have other motivations ... and that these motivations lead to quite different attitudes towards their offspring.*

- **Openness and service provision** The main point here is that an open approach can assist in counselling couples how to cope with DI and to explain the situation to their children.

In New Zealand, we might add that the Treaty of Waitangi requires policy-makers to take account of the importance of whakapapa in Maori culture, something which is not possible with the suppression of information. In this country, we should also ask the question whether DI children might not want to contact their half-siblings rather than the donor alone, and we should be aware of desires for interaction between offspring and whanau. Further, this country is now bound by the United Nations Convention on the Rights of the Child. Although assisted reproduction is not expressly addressed in the Convention, several Articles may have a bearing upon policy development. Under Article 3, the best interests of the child must be "*a primary consideration*" and under Article 7 the child "*shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by his or her parents*". By Article 8 "*States Parties undertake to respect the right of the child to preserve his or her identity, including nationality, name and family relations as recognised by law without unlawful interference*". There is at least an argument that the United Nations Convention points in the direction of a right to know of one's genetic origins.

5. OPTIONS

We explore the options for the future under two headings:

(1) the substantive policy options; and

(2) the means of implementing the policy.

A Policy Options

Anonymity

A policy of anonymous donation used to prevail in New Zealand and is still favoured in some countries overseas. Those who favour it do so on the basis that donation of semen is little different from donation of blood and is done

purely to help others out. Donors do not expect any consequences, any more than do donors of blood. It is also said that anonymity is needed in order to ensure a sufficient supply of semen for donor insemination.

On the other hand, it is now realised that semen donation does have consequences in that it determines in part the genetic make-up of the child. While social parenting may be the reality for day to day living, biological links are also part of a person's identity, and this is especially important from the Maori perspective. The experience of adoption shows that we cannot safely ignore biological origins. While it is true that many children do not know who their father is and while it is alleged that many children born into families are not in fact the biological children of the husband and wife, this is no reason to take a laissez faire attitude to ART. It is not practicable of course to regulate all natural intercourse and ensure accurate recording of parentage. But, given that it is possible when assisted technologies are used, this places ART in a different category from natural intercourse.

There is genuine concern that an openness policy will affect the supply of semen. While not wishing to underestimate the importance of this point, it must be questioned whether the concern is of sufficient significance to outweigh the importance to a person of knowing their biological origins. Furthermore, there are reasons to suppose that the semen supply might not be greatly affected by a policy of openness. First, because of the 1987 law change in New Zealand, donors should not be put off through fear of legal liabilities, eg under the Child Support Act. Secondly, public attitudes have changed sufficiently that knowledge that a man had "*fathered*" a child through donor insemination will not lead to opprobrium in the way it might have in the past. Egg donation is still somewhat novel, but if there is any public hesitation it is likely to evaporate in time when comparisons are made with semen donation. Thirdly, the greater discussion of infertility in the community may well lead to an environment where donors know to come forward and are more willing to do so. Fourthly, the experience of clinics in New Zealand is that after discussion, most of the parties to ART see the merits in openness and are willing to proceed on that basis. In fact, the emotional needs of donors can often be forgotten. Donors may more frequently in the future wish to know whether their gametes have been used to give life for a new human being.

We consider that a policy of anonymity is not suitable in the New Zealand environment. Both professional and public opinion has moved away from this approach and our guiding principles lead us inexorably towards a different approach.

Availability of Non-Identifying Information Only

The policy in some parts of the world is to limit access to non-identifying information, thus preserving the donor from actually being named, but supplying the donor with a fairly full profile of the donor. The pros and cons of the approach are very similar to those which apply to a full policy of anonymity. It is further complicated by the uncertain divide between identifying and non-identifying information. For instance, the naming of a donor's iwi might not identify the donor but from a Maori point of view that would probably not be sufficient information for the purposes of the person's whakapapa. The more information about hapu and marae that is available the better, but the more information that is given the greater the likelihood that it will identify the donor.

We see little advantage in a policy for future cases which allows access merely to non-identifying information.

Personal Choice

A further policy option, similar to that advanced by the Canadian Royal Commission, is to leave the question of the provision of information up to the parties themselves. This is in effect the position now unless altered by a radical interpretation of the Privacy Act and the Official Information Act. It is of course the position where natural intercourse is used. The issue would thus be determined by the consent forms signed by the parties, although a choice for anonymity could always be reversed by the donor at a later stage.

The advantage of this option is that it respects the personal choices which people make. It sees donation as similar to ordinary sexual relations rather than adoption. The big question mark however is over the interests of the child. The child has had no opportunity to exercise a choice and indeed if the child chooses eventually to discover genetic origins, the child will be prevented from doing so by the choice of others. This option carries with it most of the disadvantages of the anonymity model and does not address the basic objections to that approach.

Openness

We have already indicated a clear preference for a policy of openness for the future of assisted human reproduction. The arguments for and against this have already been rehearsed. The policy is consistent with the trend of practice in this country and with our own guiding principles. We believe that the principle of openness should apply to donation of gametes and embryos and to surrogacy and should now be reflected in public policy. While we are

not the first country in the world to implement such a policy, we can nevertheless see ourselves leading the common law world on this issue.

A policy of openness means that in future donation of gametes and embryos will be on the basis that the donor will be identifiable to the offspring. As part of this process, counselling of donors and parents is clearly important to enable the parties to understand the implications of donation and openness. The counselling work already done in clinics provides the foundation upon which we can build future practices. In order to exercise the right to know genetic origins, an offspring must know the background to their conception. It is hard to impose this as a matter of law, although some thought could be given to the way in which official birth certificates are drafted. Careful encouragement of parents to see the value in bringing up their children in openness and honesty may be the best answer. With the move to openness, the voice of donors should not be lost. While in the past they may have easily forgotten about being a donor, evidence suggests that the social environment is changing and donors have a genuine interest to know whether they helped give life to a child. A policy of openness should embrace ways in which the donor can be told whether a child has been born and later how that child is growing up.

If this policy option is broadly accepted, there remain some other allied issues which are discussed under the following headings.

Retrospectivity

While openness may be a generally acceptable approach for the future, how to deal with past cases which proceeded on the assumption of anonymity is much more controversial. There are three main approaches here:

1. Openness applies to future cases but not to past cases unless that was the agreed basis upon which the donation was made.

2. Openness should apply to all cases, irrespective of past assumptions.

3. A system similar to the Adult Adoption Information Act 1985 could be introduced, under which openness is favoured but (for past cases) parties have the opportunity to veto the disclosure of information if they take positive steps to do so.

The difficulty with the first approach is that it leaves a sizeable number of offspring with no effective right to know their genetic origins. With adoption, Parliament has already set a precedent for permitting a degree of retrospectivity. Clearly no law is given retrospective effect unless there are very good reasons. The reason here must turn on the welfare of the offspring

but the conflicting interests of the donor, who may claim an entitlement to privacy, must be weighed in the balance and will appear strong to many people.

The first approach becomes much more attractive if there is an effective means by which the donor can consent to the release of identifying information. This might be done by clinics taking an initiative to follow up on their donors, either when an enquiry from an offspring is made or as a general approach to all past donors. If given the right kind of information and, if need be, counselling, many donors may well be willing to waive their past anonymity.

Another option for handling past cases is to establish a "*contact*" register, similar to that which is being developed in Australia in the context of adoption. This would enable donors and offspring to put their names on the register if they are willing to be contacted, and in this way it is hoped that a degree of matching up can occur. Yet another option is to develop a veto system similar to that which applies to adult adoption information in New Zealand under the Adult Adoption Information Act 1985. This would place the onus on donors and offspring to veto contact if they did not want it. One of the main arguments for a veto system in adoption is that the birth of an adopted child in years gone by was usually as a result of extra-marital relations which were frowned upon by the society of the day. The birth mother may well have put what was for her an unhappy episode behind her and the reopening of that episode could be highly traumatic and intrusive. Under the 1985 Act, such a mother therefore has had the opportunity to veto release of identifying information about her. This is however a rather different situation from one where a man has simply donated semen or a woman an ovum. There has been no sexual encounter, no conduct which society at large frowns upon. While the appearance of the child may come unexpectedly, it should have less emotional impact than that faced by a birth mother of an adopted person.

In many ways, retrospectivity is justified by our guiding principles. But we are also mindful that we must not unnecessarily undermine the dignity of donors who volunteered their assistance under very different conditions and with an assurance of anonymity. Ultimately, a decision whether or not universal access rules should be retrospective may have to be a parliamentary one. In our view, however, much can be achieved for many people by ensuring that effective procedures are put in place for the obtaining of the consents of past donors and offspring.

Position of Parents

A possible although not frequent situation is where the parents of a child born through ART wish to find out information about the donor. The various

policy options are similar to those already discussed. If there is to be a policy of disclosure, it might be appropriate to limit access of parents and caregivers to the period prior to the child's reaching 16. This would be consistent with the rule in the Health Act allowing parents and guardians to receive information up until that age (sections 22B and 22F, Health Act).

Duty to Collect Information

At present there is no legal obligation to collect information about donors. Such information is collected as a matter of practice and is required by the RTAC guidelines. There is therefore a professional obligation to collect information but the extent and nature of the obligation is one over which there is little or no public control.

Although the current practice means that there is little problem at present, nobody can vouch for the future. We consider that the point is of sufficient importance that collection of data should be a legal requirement in New Zealand and should be tailored to suit New Zealand circumstances. Collection of donor information should therefore be a mandatory obligation under the law.

Who Should Collect the Information? A Central Agency?

At present, information is held by clinics throughout the country. This will obviously continue. However the question arises whether there should also be an official collection agency, which receives all details of births which are the result of donation. The Justice Department submission favours provider collection only and proffers four reasons for this:

- It treats ART children the same as children born as a result of sexual intercourse.

- There is a greater risk of unauthorised access to information if it is held in more than one place.

- Unauthorised access to a central record could involve the disclosure of a great deal more information than unauthorised access to a provider's record.

- A central record keeper would have to be created. The Registrar of Births is not geared to the recording of "*information that describes the total human being, or to the offering and provision of counselling in relation to the information*".

On the other hand, there are reasons for central collection:

- The issue is one which goes beyond the provider/customer relationship. Because basic human rights issues are involved, there is a legitimate public interest to ensure the availability of a fair and accessible system.

- A provider may go out of business or have records tampered with. Records could therefore be lost.

- The information may be sought many years into the future. The child may have grown up and parents may have died. It is possible that the child may not know who the provider was. It would be simpler for the child if there was a central point to turn to.

- While the Registrar of Births may have limited functions, it is hard to see why in these days of computers, a range of information cannot be easily stored and released where necessary. The task of counselling may appropriately rest with the providers. If the provider is no longer in business, another provider might be willing to assist, or in what may be rare cases, the good offices of the Department of Social Welfare might be made available.

On balance, we consider that there should be some central record-keeping, essentially to complement the role of the provider and to ensure what we regard as a public obligation to preserve essential birth information. We recommend that the Government give serious consideration to this option.

What Information Should be Collected?

With respect to the collection of information, the submission from the Department of Justice, while acknowledging that others in the community might be better able to assess what information is relevant, recommended that the following matters be included:

name of donor

date of birth

iwi or cultural affiliation

physical appearance - height, weight, build, eye colour, hair colour, complexion, any special features

occupation

educational history

talents and interests

marital status and sexes of children, if any medical history of donor and, if known, parents and grandparents.

These pieces of information will be information "*personal*" to the donor, although arguably the identity and iwi or cultural affiliation of the donor are also personal to the offspring. A similar list could be compiled covering the characteristics of the child born as a result of donation. A further valuable point is made in the submission of Vivienne Adair of Auckland University:

> *There is increasing evidence that it is not only physical and physiological traits which are genetically inherited but also a wide range of psychological traits. As well...recipients of donor gametes are recognising the importance of those inherited traits. Thus as well as basic information on health, information which would indicate the type of person a donor is would be necessary. This includes not only the surface type of information likes and dislikes, but information on attitudes, and deeper emotional functioning, learning styles and behavioral traits which are important to give insights about a donor.*

The details of what information ought to be kept will have to be carefully worked out. We enter a reminder of the principle in the Privacy Act that information should not be collected unless it is "*necessary*" for the purpose for which it is being collected.

B Means of Implementing Policy Choices

Legislation

A policy of open access to genetic information could be achieved through a special statute. This could follow the precedent of the Adult Adoption Information Act 1985. The advantage of legislation is that it can be fully tested by the rigorous of parliamentary scrutiny, with its familiar process of submissions from the public. The disadvantage of legislation is that it can take a long time to achieve and is hard to change. Given the speed with which technology and attitudes have been changing with respect to ART, it may be desirable to have a more flexible process. It may also be unnecessary to resort to legislation. If existing laws such as the Privacy Act can accommodate the policy desires in this area, then it may be more appropriate to use those laws.

If a policy of complete retrospectivity were desired, we suggest that this could be implemented only by legislation.

Privacy Act Code

The Privacy Commissioner has power to issue codes of practice. A code enables those covered by the code to depart from the privacy principles laid down in the Act and to comply instead with a specially designed information scheme. A code may not however limit a person's right to be told whether an agency holds personal information nor may it restrict the right of access to such information where that information is held by a public sector agency (section 46(5)).

A code will normally be produced only after an extended process of notification and consultation but a temporary code may be issued in situations of urgency (as has been done with the initial version of the Health Information Privacy Code). Once issued, a code effectively replaces the privacy principles in the Act and breach of the code can form the basis of a complaint to the Privacy Commissioner. A code also has a similar legal character to statutory regulations in that is can be reviewed by the parliamentary Regulations Review Select Committee.

A privacy code could set out important matters such as the information which may be kept, the rules relating to access to that information, counselling requirements, and parental involvement. The code would contain standard provisions relating to storage, correction, etc. Age restrictions are a little problematic if they are seen to breach section 46 (see above). It should be possible by means of a code to establish a contact register or veto system, but probably not a fully retrospective scheme.

There are several advantages to establishing an information regime by means of a code:

- Legislation already exists to enable legal rules to be put in place, thus avoiding the delays of the parliamentary process. More than this, Parliament has, through the Privacy Act, put in place the very kind of mechanism for handling the kind of issue we are concerned with. Where possible, such existing mechanisms should be utilised.

- A code is normally made only after consultation with the community. Even if a temporary code is issued under urgency, the code can form a useful part of the consultative process, enabling members of the community to respond to concrete proposals.

- A code can be easily amended to take account of new developments or a change in public opinion.

There are some disadvantages:

- The questions under consideration may be too important to leave to delegated legislation. Parliamentary decisions may be desirable, especially if the law has retrospective effect. However as a code has the status of statutory regulations for certain purposes, parliamentary scrutiny is possible through the Regulations Review Committee.

- It is doubtful whether a code can impose a duty to collect information.

- Section 46(5) of the Privacy Act, which prevents a code from restricting the right of access to information held by a public sector agency, may prevent a code from adequately dealing with public and private sector ART providers on the same basis (eg age restrictions).

- The production of a code rests on the willingness of the Privacy Commissioner to act. We consider that the preparation of a code has much to commend it, despite the objections mentioned. The law on access to information following ART procedures needs clarification is essential. From a cultural and human rights point of view, a set of clear rules is vital.

We consider that a temporary code ought to be issued as a companion to the Health Information Privacy Code, enabling the opportunity for further public consultation. A code costs money to prepare. Adequate funding must be made available to the Privacy Commissioner for the task of preparing a code.

Health Regulations

The Ministry of Health is proposing to issue regulations on the retention and disposal of health and disability information. Information about donation might be covered by such regulations. However, the scope of these regulations appears to be limited. It is doubtful whether they can cover issues such as a duty to keep information and access to information. The regulations deal primarily with the questions of the mode of storage of information, the time for keeping such information, and the mode of destruction. Some donor information is probably "*health information*" and so may be covered by regulations under the Health Act unless expressly exempted. The question of access to donor information is not however entirely a health issue. It is a human rights issue and therefore it may not be appropriate to envisage Health regulations dealing with all aspects of the topic anyway.

There is a case for incorporating special rules within health regulations to cover ART. However, we believe that donor information needs to be treated differently from standard health information. The reason for this is that certain donor information should be kept permanently and not disposed of after a period of time.

It would be unfortunate if information rules are spread in disparate places. It is preferable in our view for there to be one code which can be readily referred by consumers and professionals alike. We would therefore encourage the inclusion of all information rules within a privacy code, promulgated after consultation with the Ministry of Health. Health regulations should therefore exclude donor information, although other health information collected during ART procedures (eg fertility tests and diagnoses done on prospective parents) would fall within the regular rules for health information.

The Duty to Collect Information

We have indicated that the duty to keep records ought to be a legal one. Record-keeping is the first step in ensuring that participants, whether of donor insemination, surrogacy, or egg or embryo donation, have access to information. The present reliance on professional obligations, primarily through the RTAC guidelines, works well at present but questions arise whether it will always do so. If our proposals for tightening professional control over health professionals are implemented (see the "*Regulation*" chapter), then the chances of a health professional's failing to keep records is minimised. We have also recommended that the Medical Practitioners Act contain a provision that nobody can practise ART unless they come within the rules of that Act. This should catch the non-health professional who wants to make a business out of reproduction and is not too concerned about retaining information.

Four other means of ensuring the collection of information are mentioned. First, special legislation could be passed to this effect. We believe that this is probably unnecessary but if there is any doubt, an express provision could be contained in the Health Act or the Medical Practitioners Act. Regulations under the Health Act might be considered but it is not clear that the powers under that Act extend to create an obligation to collect data. It might be possible to build an obligation to collect information into the ethical standards expected of providers under the Health and Disability Services Act 1993 (s.11(2)(b)). Finally, a provision might be included in the Consumers' Rights Code to be made under the forthcoming Health and Disability Commissioner Act.

6. CONCLUSION

Work on this chapter has been done in consultation with the Privacy Commissioner and his Office. We are very grateful for their assistance. We have recommended that the future policy in relation to donation for human reproduction should be one of openness. The best means of implementing this policy is a code under the Privacy Act. With adequate funding, we consider that the Privacy Commissioner is in the best position and has the necessary statutory powers to consult widely and to produce a generally acceptable code. Overall monitoring of the developing needs of all parties should be a responsibility of the proposed Council on Assisted Human Reproduction.

CHAPTER 9

EMBRYOS AND GAMETES

1. INTRODUCTION

One of the consequences of the new conception technology is that human embryos can be created and stored for long periods. Semen has been stored for a much longer time, and in the near future it is likely that the technology will have developed for the successful freezing of ova. These procedures raise some common questions: what is to happen to "*spare*" embryos and gametes? May they be used for donation purposes? May they be used after one or both of the gamete providers has died? May they be the subject of testamentary disposition or matrimonial property division? Can they be bought and sold? Can they be used for research, or produced especially for research purposes?

Often the debate focuses on embyros. When the ability to freeze ova is improved, the nature of the debate may well change, and some people's anxieties may be considerably lessened. Even so, there will continue for some time to be frozen embryos held in New Zealand clinics and the issues surrounding them must be addressed.

2. VIEWS ON GAMETES AND EMBRYOS

The moral status of an embryo (in particular) is a matter of acute division of opinion throughout the world. For some, life begins at conception and moral rights and obligations apply. For example, the Catholic Archdiocese of Wellington stated:

> *There is no point following conception where the human individual suddenly becomes human life. Life begins at conception and ends at death. In between, life does not develop, it is simply there. What does develop is the morphological structure, the physiological performance of the structure, behavioural traits and personality.*

A different religious view comes from an Anglican priest who commented to us on the question of the status of the embryo:

> *The extremes of opinion provide intellectual ease for those uninvolved, but not always justice and compassion for those who are involved. My own view is that the embryo is not yet a person and therefore disposal of the embryo for example is less of a problem than disposal of a newborn baby.*

The National Council of Women perhaps reflected public opinion as well as anyone:

> *Our members display the plurality that exists in society, some believe that human life begins as soon as the sperm and ova have united and should be treated with respect and dignity from then on, while others believe that human life begins when the foetus is viable.*

The view is also sometimes expressed that the embryo is "*potential*" human life, but while this is true, the same can be said about gametes, and in neither case does the reference to potentiality indicate what tangible rights might flow to the benefit of the embryo or gametes.

The Warnock Committee in the United Kingdom was divided in its recommendations on research on embryos. Its main recommendation was that research should be permitted up until 14 days when the primitive streak appears but three members dissented, holding to the opinion that no research should be permitted. The Canadian Royal Commission recommended that decision regarding the disposition of zygotes should be made by women and couples before gametes are retrieved or zygotes created, but that zygotes should not be stored for more than five years or after the death of one of the gamete providers. They accepted that research on embryos could be conducted but only during the first fourteen days of development and only with the fully informed consent of those who donated the gametes. Further, they thought it acceptable to create zygotes for research purposes but only if this involved no additional invasive procedure for the woman, eg where she was already undergoing surgery for other purposes, the collection of her eggs with her consent would be permissible.

3. OUR APPROACH

Our approach is based on the principles which have guided us. In view of the wide divergence of opinion on the moral status of the embryo, we do not believe it is possible to base policy on one particular view. Consensus might emerge after further debate, but we doubt it. Furthermore, whatever moral view is taken of the embryo, it does not follow that law and policy must inevitably be the same. There remain areas where the law must allow genuine differences of moral persuasion. Legal and moral status do not necessarily coincide.

A better basis upon which to find common ground is to regard all human tissue and body parts as tapu and sacred. This means that not only an embryo but also gametes should be treated with dignity. Appropriate rules and procedures are therefore needed to ensure that gametes and embryos are not handled with reckless disregard for their origins.

In our view, the integrity and dignity of those involved requires that the primary decision-makers with respect to the disposition of gametes and embryos should be the gamete providers. This enables these people to exercise their own moral and cultural decision-making power. So, for example, the couple who object to

embryos being used other than for re-implantation can limit the use of their embryos accordingly. Likewise, where a Maori gamete provider dies, cultural practices calling for that person's tissue to be buried with the deceased could be catered for by the parties making their own culturally appropriate choices.

4. THE PRESENT LAW

The law relating to embyros and gametes is far from clear. Writers have debated whether there can in law be "*property*" rights over embryos and gametes and analogies have been drawn with other human body parts (an excellent discussion is by A Grubb "*The Legal Status of the Human Embryo*" in *Challenges in Medical Care* get ref). Concern over the "*property*" analysis stems from the consequences: if an embryo is an item of property, it ought to be able to be bought and sold, it would be the subject of matrimonial property division, testamentary disposition (a proposition recently accepted in a US case: see *Hecht v Superior Court* 20 Cal Rptr 2d 275 (Cal Ct App 1993)) and a raft of other laws affecting personal property. The alternative approach is one which treats the embryo as if it were a child, the parents having parental rights and responsibilities with respect to the embryo. This approach is also problematic: handling the embryo could be an assault or even murder if the embryo dies, the embryo would have inheritance rights even before implantation, and would embryos need passports if they travelled?

Issues over gametes and embryos have arisen only occasionally in courts around the world. In one case where an embryo was deliberately destroyed by a doctor, damages for emotional distress were awarded to the couple who provided the gametes.[1] In *York v Jones*[2], where the couple wished to move to another clinic, the court ordered the original clinic to hand over the couple's frozen embryos so that they could be used at the new clinic. In *Parpalaix* v *CECOS*[3] a French court ordered the frozen sperm of a widow's late husband to be returned to her because of an implied term in the agreement between the husband and CECOS that the sperm be returned to the person for whom it was intended. A similar approach would probably have been taken to frozen embryos.

Perhaps the most fascinating case on embryos is the decision of the Supreme Court of Tennessee in *Davis*[4]. Here the dispute was between a divorcing husband and wife. While much of the judgment turns on American constitutional arguments which do not automatically apply in New Zealand, the general approach is one that might find favour with the courts here. The wife, at least initially, wished to have control over the embyros in order that they could be implanted in her, later changing her mind and wishing that they be donated to a childless couple. The husband was opposed to having another child by his estranged wife. The court reached the following general conclusions:

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[1]*Del Zio v Columbia Presbyterian Medical Centre* (Unreported 14 November 1978, New York Federal District Court)
[2]717 F Supp 421 (1989)
[3]1984 Tribunal de Grand Instance de Creteil. CECOS is the Central d'Etude et de Conservation des Oeufs et du Sperme
[4]842 SW 2d 588 (1992)

- Embryos are not "*persons*" under the law and do not enjoy the protection that the law gives to "*persons*".

- Embryos are not "*property*" but occupy an interim category between "*person*" and "*property*" that entitles them to special respect because of their potential for human life.

- Any agreement on the disposition of embryos should be presumed valid and be enforced as between the progenitors.

- The right of procreation is a vital part of an individual's right of privacy under the Constitution and authority to decide what to do with embryos rests with gamete providers alone. The State's interest in potential human life is insufficient to justify infringement on gamete providers' procreational autonomy.

- Where there was a dispute between the gamete providers and the matter was not resolved by a prior agreement, ordinarily the party wishing to avoid procreation should get custody of the embryos. Where however the other party has no reasonable alternative possibility of achieving parenthood, an argument in favour of their obtaining custody should be considered.

What is the likely state of New Zealand law? Any answer is inevitably speculative. The notion of embryos having legal personality can be rejected with some certainty. Courts around the world, including New Zealand (cf *Wall v Livingstone and Roborgh* (1982) 1 NZFLR 417) have consistently rejected arguments that the fetus has legal personality. Vesting such personality on an embryo would be quite inconsistent with well established precedent and with the present abortion laws. The "*property*" approach to embryos is less clear but it is probable that a New Zealand court would follow the weight of overseas authority to the contrary. An analogy can however be made with the Human Tissue Act 1964, which deals with the use of body parts including organs after a person's death. The first rule under that Act is that the express wishes of the deceased may be followed by, for instance, the hospital in possession of the body at the time of death. In the absence of such wishes, body parts may be used, subject to reasonable enquiries of the family. The underlying policy of these rules is to give pre-eminence to the wishes of the provider of the body parts (Justice Department submission). By analogy, priority should be given to the wishes of the providers of gametes and embryos.

5. OPTIONS

The Government has the option to adopt either the "*property*" approach, the "*legal personality*" approach, or an alternative approach. For reasons covered in the preceding section, we do not consider the first two options possible in the New Zealand environment. The property approach fails to give due regard to the mana of the human tissue and would open the door to trading in blood, organs and

other human parts. The personhood approach would be defensible only if there was a radically restrictive abortion law, which Parliament has set its face against. The alternative approach is to grant dispositional power to the gamete providers, and, as we have mentioned above, this is the option we favour. The question is how to achieve this goal.

Legislation

It would be possible to set out in detailed legislation the powers of the gamete providers and the result where the wishes of those persons have not been expressed. At this stage, however, it is not clear to us that this is either necessary or desirable. First, it is likely that the courts, if faced with an issue over the disposal of gametes or embryos, would look to the terms of the contract between the clinic or storage agency and the couple. The law of contract already offers a legal framework into which the option under consideration can be fitted. Secondly, views on the detail of such legislation may differ and may well change dramatically overtime. This is the very kind of issue that might be much better left to incremental development.

A Code

The use and disposition of gametes and embryos could well be an appropriate subject for the preparation of a code by the proposed Council on Assisted Human Reproduction. Such codes would make sure that couples are properly counselled, think about the alternative uses for their gametes and embryos, consider what might happen in the case of death or separation, and then make informed decisions as part of their agreement with the clinic.

The Courts

Situations could simply be left to come before the courts as they arise. There is no guarantee, however, that the New Zealand courts will ever be faced with deciding the fate of gametes and embryos. It is preferable, in our opinion, to be more proactive and ensure through the overseeing role of the Council that provision is appropriately made in the arrangements between clinics and gamete providers.

Specific Restrictions

Some people are in favour of specific statutory restrictions on what may be done with embryos. Limitations on research are a prime example of such restrictions. Research is discussed in a separate chapter. Suffice it to say that we are not aware of such research occurring in New Zealand or being proposed. Should such research be contemplated, it is for all practical purposes certain that it would have to be passed by either the Health Research Council's Ethics Committee or the National Ethics Committee on Assisted Reproductive Technologies. There are,

therefore, mechanisms already in place for controlling embryo research in this country and legislative action appears to us to be unnecessary.

OVERALL REGULATION

If our recommendations made in the "*Regulation*" chapter are accepted, ie the establishment of the Council on Assisted Human Reproduction and the closing of loopholes with respect to professional control, we are confident that there will be fewer problems with embryos and gametes.

CHAPTER 10

RESEARCH

INTRODUCTION

Research is a normal and essential part of any developing technology. ART is no exception. ART differs from other technologies in that it involves the sanctity of human tissue, the potential of procreative ability, the anguish of involuntary childlessness and intense public interest.

In ART, the main research issues are:

- The balance between biomedical, psychosocial and health service research
- Documenting the outcomes of policy decisions
- The role of the state
- Defining the parameters of research
- The process for debating contentious issues

CURRENT PRACTICE

While research into biomedical and technical aspects of ART progress, those that document and inform debate about social, psychological and cultural outcomes are not readily supported yet, we believe these are just as important. Some New Zealand researchers, including Vivienne Adair of Auckland and Ken Daniels of Christchurch, have recognised the importance of this and have already begun research in this area which has achieved international recognition. Furthermore, as major decisions which will shape the future of health services in New Zealand are being considered, information about how infertility affects quality of life issues would be valuable.

In New Zealand, we have made policy decisions which are different from many countries to whom we usually have significant parallels. We are encouraging openness in families so that offspring are informed of those people who contributed to their conception, nurturing and development, be they donors,

surrogates or social parents. We have recognised the cultural needs of Maori to know whakapapa and this, together with our experience in adoption has led us to a policy that offspring should be able to access information about their genetic origins. Because this policy is different from those in many other countries, we are unlikely to be able to draw parallels from overseas research and this compounds the need to monitor outcomes and evaluate their impacts on society, families and individuals.

The State in its various roles of funder, lawmaker and protector, has a legitimate interest in ensuring adequate research and development, as well as monitoring and evaluative research occurs to allow informed decision-making about ART.

THE FUTURE

We do not doubt that some research techniques which are available or being developed would be repugnant to many New Zealanders. Some countries have responded to these technologies by introducing legislation which bans them thereby delineating the parameters of research.

The Canadian Royal Commission, for example, recommended that:

> *Legislation prohibit, with criminal sanctions, several aspects of new reproductive technologies, such as using embryos in research related to cloning, animal/human hybrids, the fertilisation of eggs from female fetuses for implantation, the sale of eggs, sperm, zygotes or fetal tissue, and advertising for, paying for or acting as an intermediary for preconception (surrogacy) arrangements.* (p xxxii)

Submissions to us also suggested that there was a need to ban, through legislation, the outer limits of ethical acceptability. However we believe the legislation should not comment on an exhaustive list but rather should draw a boundary. A process should then be put in place to deal with the second tier of contentious decisions and promote informed public debate.

Aspects of this task are currently performed by the National Ethics Committee on ART, and the Ethics Committee of the Health Research Council. We believe that the proposed Council for Assisted Human Reproduction could assist in this process by preparing discussion documents and mapping the outcome of debate and decisions.

The other aspect of research which will need future consideration is how to ensure adequate monitoring and evaluation occurs about the long-term outcomes of our current policy decisions. Realistically this is only likely to occur if it is fostered with resources and by ensuring adequate information is recorded. The Health Research Council and other state funded agencies for research into science and technology should recognise the importance of monitoring the social outcomes related to technology and ought therefore to be receptive of proposals for such research.

Separate funding for research from the Government could be given to the proposed Council of Assisted Human Reproduction to underline commitment to this task.

OPTIONS

(a) Legislation

There is merit and significant public support for delineating the extreme forms of research that could not be contemplated in New Zealand in the foreseeable future. We believe that this option should be incorporated into legislation at the first appropriate opportunity.

(b) Use of Existing Institutions

A second tier of debate and decision-making could build on existing institutions such as NECART and the Ethics Committee of the HRC. The proposed Council for Assisted Human Reproduction could establish a process which promotes informed public debate and canvasses opinion about a range of ethical issues.

We believe that this option is an important complement to option (a).

(c) Government to Consider Funding Research in ART

While state funded research institutions exist, the Government may wish, through its policy ministries, to commission research which follows the long term outcome of current policy decisions.

We believe this option should be considered together with (a) and (b).

SUMMARY

We believe that the state in its various roles, as funder, lawmaker and protector has a legitimate interest in overseeing research in ART. We particularly note three issues, legislation to clarify absolute parameters, a process for debate and decision-making and the need to ensure adequate monitoring of policy decisions.

CHAPTER 11

SURROGACY

1. WHAT IS SURROGACY?

Surrogacy usually occurs where a woman has agreed to carry a child for another couple, part of the arrangement being that the woman will pass the child to the "*commissioning couple*" after birth. Surrogacy may take a number of forms but the main ones are:

- The woman is inseminated by natural intercourse with the semen of the commissioning husband.

- The woman is artificially inseminated with the semen of the commissioning husband.

- The woman has had implanted in her womb an embryo which has been created by the gametes of the commissioning couple.

- The woman has had implanted an embryo which has been created by the ovum of the commissioning wife and semen donated by another male, or by a donated ovum and the husband's semen, or is an entirely donated embryo.

Surrogacy may sometimes involve an intermediary who has acted as a "*broker*" in setting up the arrangement, a lawyer who has prepared a surrogacy "*contract*", and a clinic which has carried out the procedure. On the other hand, the arrangement may have been made by the parties themselves. This can occur where, for example, a sister or close friend has agreed to act a surrogate. Some Maori have commented that the word "*whangai*" means "*to nurture*" and that this arrangement usually occurred some time after the birth of a baby for a variable length of time. However, with technology, women can now literally "*whangai*" an embryo and in this process they may become surrogate mothers.

Surrogacy may involve the payment of money, either to cover expenses or as a fee for the surrogate's services, or may involve no monetary or other exchanges at all. A distinction is sometimes drawn between

- commercial surrogacy; and

- altruistic or compassionate surrogacy.

Between these two categories, there may be different shades of arrangement, eg where an essentially altruistic arrangement involves some monetary exchange to cover loss of income.

2. DOES SURROGACY OCCUR IN NEW ZEALAND?

There is no doubt that surrogacy does occur in New Zealand but it is very difficult to determine its prevalence. The reason for this is that currently no surrogacy is done by the established clinics and so, surrogacy is an informal process for which there are no records. What evidence we have received is anecdotal and our conclusion is that while there is some surrogacy carried out in New Zealand, it is not on a vast scale and tends to be surreptitious. In addition, some New Zealanders will travel overseas to jurisdictions which permit surrogacy and where surrogacy is well organised. This "*procreative tourism*" may be a matter of concern, especially for the welfare of the child but it is hard to see how other than a totalitarian government, could prevent New Zealanders travelling abroad for such purposes.

While a limited amount of surrogacy is doubtless occurring - using both natural intercourse and "*do-it-yourself*" artificial insemination - we are aware that there are people who would like to take advantage of surrogacy techniques through professional and accepted agencies. Several of these people are keen to use IVF surrogacy on a compassionate basis. For various reasons, a woman may be able to produce ova but be unable to bear a child or the risk to her health is too great. It is also possible that a woman may not want to bear her own child for social reasons, eg so as not to interrupt her career. The people who have approached clinics fall into the first category.

Our information is that IVF compassionate surrogacy has occurred in New Zealand with ethical approval but the pregnancy ended in a miscarriage. Applications by other clinics were, for some time, stalled by ethics committees who felt unable to reach a decision. Finally, after its establishment in 1993, the Interim National Ethics Committee on Assisted Reproductive Technologies considered and rejected an application for IVF surrogacy. The consequence of this decision is that New Zealand clinics do not offer surrogacy at all. While surrogacy is not as such contrary to the law (although see our later discussion), the clinics are bound for professional and accreditation reasons to act with formal ethical approval. A clinic which acted in the face of a refusal by an ethics committee would run the risk of professional disciplinary procedures and a loss of accreditation with RTAC. IVF surrogacy is not likely to take place in New Zealand unless ethical approval is given or unless there is a new statutory scheme permitting surrogacy.

3. THE LAW

There are various aspects to the current legal position as it affects surrogacy. In summary, the issues are as follows:

- What is the status of the child born as a result of surrogacy?
- How would the law handle an application for guardianship or custody?
- Can an adoption follow the birth of a child through surrogacy?
- Is the arrangement between the surrogate and the commissioning couple binding in law?
- Can payments be made to the surrogate?
- What is the legal position of an intermediary?

The answers to some of these questions may depend on whether surrogacy was by assisted means or by natural intercourse, and whose gametes were used.

(a) Under the Status of Children Amendment Act 1987, if assisted means have been used, the birth mother (the surrogate) and her legal or de facto husband (if he consents) will be the legal parents of the child. This rule applies even if the surrogate has no genetic connection with the child. As this is contrary to the intentions of the parties, the position of the commissioning couple can be regularised by custody and guardianship orders or more satisfactorily by adoption. Where the surrogate has no husband, it appears that the commissioning father is the legal father but has no legal rights or responsibilities with respect to the child. If natural intercourse has been used, the legal position is less straightforward. The surrogate would be the child's legal and genetic mother and her legal husband (but not her de facto partner) would be presumed to be the legal father by virtue of section 5 of the Status of Children Act 1969. This presumption could be rebutted if evidence of intercourse with the commissioning father was produced but this might be insufficient without blood and DNA tests to back up the evidence of intercourse. If the evidence convinces a court that the father of the child is the commissioning father, then a paternity order could be granted. Again, if the child is being brought up by the commissioning couple, it may be necessary to regularise the situation by adoption.

(b) If a dispute arose between the surrogate and the commissioning couple over who should have care of the child, the Family Court might be faced with a custody application under the Guardianship Act 1968, coupled possibly with an application for guardianship rights to be vested in the commissioning couple. The touchstone for handling such applications is the welfare of the child, which is the first and paramount consideration. Generally speaking (but not always) where the question has arisen overseas, this test has been used to resolve matters. Because our legislation clearly provides for

the paramountcy of the child's welfare, we are in no doubt that this would be he governing factor in any dispute in New Zealand. An alternative possibility is that the Children, Young Persons, and Their Families Act 1989 could be used to determine what is to happen to the child. This Act operates where there has been some abuse or neglect of the child and therefore is likely to be relevant in surrogacy cases only in exceptional situations. Where the 1989 Act is invoked, a family group conference would be the initial forum to try and decide on the child's future. Nevertheless, following amendments to the legislation in 1994, the welfare of the child will still be the paramount consideration.

(c) Where a child is adopted, full parental rights and responsibilities are passed to the adopting persons, to the exclusion of all other persons. Where the commissioning couple have adopted a child, then in law they are treated as the child's parents for all purposes. If the commissioning couple are bringing up the child and the surrogate has no involvement in the child's life, adoption is arguably in the interests of the child in order to secure the child within the family to which it belongs socially. But this overlooks the role of the birth mother. Under current law, the birth mother and sometimes the father (this usually means the surrogate's husband even where he has no genetic connection with the child) must consent to the adoption. Where there is a refusal to consent, the Family Court may dispense with the need for consent but only in exceptional circumstances, where the birth mother has effectively abandoned the child.

Before making an adoption order the Court must also be satisfied that the adopting parents are fit and proper persons to have custody of the child and that the adoption would promote the welfare of the child. These are essentially matters to be considered on a case by case basis by the Court. Two particular matters could affect the decision. If payments are made to the surrogate in breach of the Adoption Act (see below), a court might question whether the commissioning couple are fit and proper. Likewise the child may have been placed with the commissioning parents in breach of section 6 of the Adoption Act. Under section 6, if a child is placed with someone for the purposes of adoption, a social worker's report is first required, but breach of this provision does not automatically prevent the court from making an adoption order.

(d) The legal status of the arrangement between the surrogate and the commissioning parents has not been tested in the New Zealand courts, although it has been the subject of differing judicial and legislative responses overseas. Our advice is that, although the arrangement is probably a contract, a New Zealand court is likely to hold it void as against public policy and render it unenforceable. As already discussed, the placement of a child is subject to the

overriding test of the child's welfare. This cannot be made subject to the private bargaining of the parties. If the surrogate has suffered pecuniary loss or the commissioning couple have made payments for no return, the parties may still have a remedy in quasi-contract. A surrogacy arrangement may be an illegal contract if, for instance, it provides for payments in contravention of the Adoption Act. Some relief from hardship could be obtained under the Illegal Contracts Act. Other laws, such as those determining the legality of abortions, would also, it is suggested, take priority over any surrogacy arrangment.

(e) The question of payments to a surrogate has been tested in the New Zealand courts. In Re *P* (*adoption: surrogacy*) [1990] NZFLR 385, Judge McAloon held that payments made to the surrogate to cover maintenance and birth and legal expenses were not in breach of section 25 of the Adoption Act which prohibits payment in consideration of the adoption of a child. As the surrogacy had occurred through natural intercourse, the commissioning father would have been potentially liable to make such payments anyway under sections 79-81 of the Family Proceedings Act 1980. Had the surrogacy been achieved through assisted means, the obligation to make payments would have been less straightforward, but unless they were directly tied to the adoption eg if money was paid in return for the birth mother's consent to adoption, it is hard to see how the payments could be impeached. In Re *P* (*adoption: surrogacy*), the court granted an adoption order, as the birth mother had consented, there was support from the Department of Social Welfare, and there was in the end nothing to question the adopting parents' suitability to be parents.

(f) The position of the intermediary is untested. There may be a contract between the intermediary and the commissioning couple, and between the intermediary and the surrogate. Where the intermediary is, for example, a lawyer who subsequently prepares the case for adoption, this will be treated like any other professional arrangement. Likewise, the relationship between a clinic and the parties is probably an ordinary professional arrangement. Where the intermediary is a "*broker*" who advertises on that basis and whose purpose is purely to arrange the surrogacy, any contract may stand or fall depending upon whether the surrogacy arrangement is void or illegal. A void or illegal arrangement may render the contracts between the broker and the commissioning couple and the broker and the surrogate void or illegal. Criminal offences might also be committed, for example under section 149 of the Crimes Act 1961 which makes it an offence, for gain or reward, to procure or agree or offer to procure any woman or girl to have sexual intercourse with any male who is not her husband.

Overall Comment on the Law

While there are doubtless unanswered questions in the law relating to surrogacy, the law on some key issues can be relatively easily stated, the most important being the status of the child. Those points which remain outstanding can be resolved by the courts as the need arises. There is a legal framework which governs surrogacy. Whether it is the appropriate one for New Zealand's conditions is a different matter, upon which there are differing views.

4. APPLYING OUR PRINCIPLES TO SURROGACY

Surrogacy is a topic which can lead to people taking very fixed positions for and against. Varieties of religious, philosophical and feminist attitudes emerge, but at the end of the day there is little consensus. The issue divided the Warnock Committee in the United Kingdom. In the United States, the Uniform Status of Children of Assisted Conception Act offers a model of judicial approval of surrogacy arrangements. A working group of the Australian National Bioethics Consultative Committee recommended controlling surrogacy through licensed surrogacy agencies but subsequently Australian Health and Social Welfare Ministers took the view that a number of activities associated with surrogacy should be made criminal offences. Some states in Australia and a number of European countries have in effect attempted to ban surrogacy.

The submissions made to us represented a range of views on surrogacy. Perhaps the most passionate pleas have been made by those who have been negatively affected by INECART's refusal to approve IVF surrogacy and this issue was important to providers. But it is also true that other people have expressed total opposition to all kinds of surrogacy. By and large, consumers were concerned to gain access to basic ART services, whereas surrogacy is more rare. Several public bodies were willing to countenance (at least) intra-family surrogacy, including the Commissioner for Children, the Ministry of Health (in the context of whangai), Ministry of Women's Affairs, Department of Social Welfare and the Department of Justice. The Women's Health Action Trust has mixed views on surrogacy:

> *We are unanimous in agreeing that commercial surrogacy or stranger surrogacy should be banned, however, some of us feel that intra-familial surrogacy using a couple's gametes should be allowed, as the child would be reared within a wider family circle which included genetic parents and gestational and birth mother. Similar arrangements have been traditionally used within both the Maori and Pakeha communities. However, this concept (and we dislike the term 'compassionate surrogacy' as too emotive) does not include friends, as this would lead to manipulation of the law. Others in our group disapprove of this arrangement as they feel there could still be conflicts over who is the mother of the child, especially in the event of marriage breakdown.*

The New Zealand Infertility Society supports surrogacy in cases of medical need and subject to regulation. The Society does not support any party's making

financial gain out of surrogacy and believes that the off spring should have access to information about birth and genetic origins.

There is a considerable literature on the surrogacy debate which we cannot hope to reflect. Rather than rehearse all the arguments for and against surrogacy, we have decided to examine surrogacy in the light of the principles which have governed our thinking. In applying these principles we have been conscious of the spectrum of different kinds of surrogacy.

Ethic of Care

Adopting the ethic of care means that we cannot take an absolute ideological stance that surrogacy is either always good or always bad. Rather than advancing a rule which will apply in all situations, we need to consider the various factors which operate in surrogacy. In the end we must ask whether the best interests of the individuals and the community at large are advanced by surrogacy. Put this way, we consider that surrogacy situations may often need to be judged on their individual merits. At one end of the spectrum, where profit-making is the primary motive, we would have serious doubts whether the welfare of the people concerned is given sufficient priority, and the State's responsibility to protect children may mean that such surrogacy arrangements ought to be discouraged. At the other end of the spectrum, where family formation is the motive, the parties have all consented and there is good reason to suppose that the child will be well cared for and nurtured, the ethic of care may favour such arrangements proceeding.

Respect for Human Life and Dignity

The argument is sometimes raised that surrogacy treats children as commodities which can be bought and sold. If this is so, then the dignity of children and of the buyers and sellers is lowered. But whether all surrogacy can be described in this way is doubtful. If it can, then the argument proves more than it desires, for virtually all attempts to seek assistance to have children - whether using a "*high-tech*" procedure or not - and other common practices such as adoption may be tarred with the same brush. It is also said by some that surrogates degrade themselves and women as a whole by participating in the process. This may be true in some instances, but, unless this position is taken as an unarguable a priori assumption, whether it is always true is a matter of evaluating the empirical evidence. We consider that the effect on the dignity of women should not be judged by assumptions but by looking at the situations and people involved. Another perspective, especially in relation to altruistic surrogacy, is that the dignity of the woman is enhanced both by her taking responsibility for her own decision-making and by acting for the benefit of fellow human beings.

The technology used in surrogacy is not special. It is basically the same as that which is used in other assisted reproduction situations. In itself therefore the technology affects human dignity no differently from comparable situations

involving assisted reproduction. What may affect human dignity is where the parties are not made fully aware of what is involved, including the medical, social, psychological, legal and ethical aspects, and are not given the chance to freely decide whether to participate. Fully informed consent, freely given, is therefore essential.

From another point of view, the denial of surrogacy through professional clinics may force some people to seek degrading and expensive alternative means of achieving their aims. We do not consider human dignity is advanced by driving people offshore and into "*reproductive tourism*" or to use back-street entrepreneurs. The involvement of surreptitious brokers or a hard-sell intermediaries cheapens the beginnings of life and lowers respect for people taking part.

Autonomy

This principle would favour minimal State intervention in surrogacy. The freedom to decide how to act, so long as it does not harm others, is a fundamental one in a democratic society. Those who wish to ban surrogacy do so at the expense of a cherished value and the case for doing so must be very clear. On the other hand, a middle view is that, while surrogacy ought not to be banned, it should be regulated and made subject to safeguards. Given potential risks to the parties, this position might be an easier one to sustain in the face of the principle of autonomy.

Treaty of Waitangi

The understanding of family and parenting held by many Maori may bare different from those of Pakeha. Forms of family arrangement which may be seen as a variety of surrogacy have been practised for centuries. The Treaty recognises a relationship between Maori and the Crown. The Crown has a duty as part of good government to protect Maori constitutional rights by ensuring that the processes of ART, including surrogacy, are culturally safe and open.

Justice

Arguments under this heading run in opposite directions. One position is that the unavailability of surrogacy discriminates against infertile couples, and could even breach the Human Rights Act protections against those with disabilities (see further, our chapter on "*Discrimination*"). For a number of people, surrogacy is the only means of having "*their own child*", and in this sense becomes the only medical alternative.

On the other hand, others raise the potential for exploitation inherent in surrogacy. There is a fear that women particularly from lower socio-economic sections of the community and possibly of particular ethnic backgrounds will be used (or abused) because of their need to find extra sources of income. There are also risks ordinarily attendant on pregnancy and child birth in becoming a

surrogate. Some risks are not predictable and may occur despite full precautions and the best management. Some women may not be able to appreciate these risks fully until it is too late. Exploitation is not necessarily a one way process. There is also potential for exploitation of the commissioning parents, who, because of their medical situation, may be vulnerable, be misled as to the background of the surrogate, and be forced into paying considerably more money than might be appropriate.

Arguments about exploitation have been critiqued on the basis of a lack of hard evidence (are women in fact exploited, do they act from improper motives, are they all weak and vulnerable?) and because, if women are intrinsically exploited, is this not because of the general nature of male/female relationships rather than something peculiar about surrogacy? There is also an argument that reference to exploitation is patronising. So long as there are proper safeguards such as informed consent, why should women be told what they can do with their bodies?

It is hard to draw firm conclusions from these arguments, except that any system should have safeguards to protect the vulnerable - here this means all parties, the surrogate, the child and the commissioning couple. What these safeguards should be is another issue upon which there will be differences of opinion.

The principle of justice incorporates the notion of legality. We refer back to our chapter on "*Principles*" in which we discuss international instruments including the right "*to marry and found a family*".

Best Interests of the Offspring

We have already alluded to the notion that children may be treated as commodities. Another aspect of the welfare of offspring is their psychological wellbeing. How will a person who learns that they were born through a surrogacy arrangement cope in later life? Is the possibility of psychological harm not enough to avoid surrogacy in the first place? The difficulty with this line of reasoning is twofold: first it is largely speculative, as we do not know what the psychological effect is and it could just as easily be claimed that it is in the best interests of the offspring first to be born and then to be nurtured by parents who very much want a child; secondly, there are many children who are brought up other than by their birth mother. This may be because of adoption, fostering, cultural practices or very commonly separation and reblending of families. Should surrogacy be treated differently from these other social phenomena? A further aspect of the offspring's best interests is safety, which is discussed below.

Right to Know Genetic Origins

There is a real risk if surrogacy takes place overseas or in informal ways, that no proper records will be kept and that the child may never be able to know about genetic origins. This then is an argument for making surrogacy part of a transparent and accountable system.

Accessibility

Surrogacy through accredited clinics is likely to be more accessible and affordable than if the parties are forced to find alternative options.

Quality Services and Accountability

There are risks involved in back-street surrogacy. These include health risks relating to conception, pregnancy and child birth. Accredited clinics are more likely to ensure safety standards and are accountable through RTAC, ethics committees, their professional organisations, and their standing with consumer groups.

Overall Comment

The ethic of care and the principles which have guided us lead to the view that dogmatic positions on surrogacy are difficult to sustain. There are risks in surrogacy, and some activities - including profit-making entrepeneurism, procreative tourism, back-street arrangements - should not be encouraged. But there is a spectrum of forms of surrogacy and a range of motivations. To treat all forms as if they were the same will lead to other risks and injustices. The State does have a proper protective role in relation to surrogacy. It appears to us that what is needed are appropriate protections and ongoing monitoring of what is happening in New Zealand.

Openness with respect to surrogacy is important. The relationship between the surrogate and the child with respect to imprinting or bonding occurring during pregnancy is neither denied nor minimalised if the surrogate and family relationship is open. IVF compassionate surrogacy, while not contributing genetic material to the offspring can be seen as much a gift as donating sperm, given however that it takes much more time, involves more risk, and is no less intimate. Relationships should be as open as for sperm donation. Such openness may be hindered if surrogacy is driven underground or overseas. The difference between morality and law must also be considered. Some may take moral objection to surrogacy. That however does not automatically mean that the law should reflect morality. That something is adjudged immoral is one thing; how it should be treated by public policy is another. The question may be put in another way: is surrogacy in the end a matter of personal morality that should not be the law's business? In a pluralistic society, this question must be constantly asked in order to avoid the imposition of a dominant set of values on minorities. As we have indicated, we believe that there is a legitimate public interest in surrogacy but the working out of that interest is complex and not yielding of simple solutions.

5. IVF COMPASSIONATE SURROGACY

The issue of IVF compassionate surrogacy is one which has aroused the most acute interest in the community because of INECART's decision to refuse ethical approval to a provider for IVF compassionate surrogacy. As there are couples living in hope that the decision will be reversed in the future and because IVF surrogacy is the only way in which they can have their own genetic child, we consider that our views ought to be made clear.

Our opinion is moulded in large part by the application of the principles we have just discussed. IVF compassionate surrogacy is at the end of the spectrum which raises fewest qualms about commercialisation, exploitation and harm to the participants, including the child. Indeed, it is important in examining the ethical implications of IVF compassionate surrogacy not to be beguiled by some of the phrases which are often applied to the other end of the surrogacy spectrum. The analysis must be more sophisticated than this. There are furthermore positive aspects to IVF compassionate surrogacy - it enables a couple to have a child in circumstances where back-street surrogacy is not an option, although travel overseas might be. It removes a possible source of discrimination against a group which suffers from a particular kind of disability. The child will be brought up by two parents to whom the child is most likely to be biologically related. While the feelings of the birth mother will not be insignificant, in IVF surrogacy where a friend or sister has acted as surrogate the birth mother is more than likely to see the child grow and be part of the child's extended family and life.

We have no objection in principle to IVF compassionate surrogacy. In particular cases, eg where the parties appear not to appreciate what IVF compassionate surrogacy involves or where there is doubt about the genuineness of consent, it would be appropriate to refuse to proceed. This however is a matter of looking at each case on an individual basis.

We do not therefore agree with INECART's refusal to grant ethical approval. The Interim Committee gave six reasons for its refusal, none of which, with respect, we believe justified the decision. We appreciate the care and effort which the Committee devoted to the issue and we in no way question the bona fides of the members of the Committee. We consider nevertheless that, for such an important decision, the Committee ought to have given much fuller reasons for its conclusion.

Given that our position is in sharp contrast to that of the Interim Committee, we feel we owe it to the Committee to address its reasons directly:

- "*The lack of an adequate legal framework in New Zealand for surrogacy arrangements generally*" - As discussed above, there is a legal framework for surrogacy, although some may wish it changed. The ethics committee structure should be seen as part of that structure. Unless there were a law, which for instance banned a particular

activity, there is no reason why a decision on ethical propriety should not be made.

- "*The absence in New Zealand of Government decisions on legislative requirements in relation to surrogacy*" - This is similar to the first reason but almost suggests that the Government or Parliament should make the decision about IVF compassionate surrogacy. This however is to confuse law and ethical approval. It is difficult to see why this particular ethical decision should have to await Government action when the Government appointed INECART especially to deal with such issues.

- "*The degree of uncertainty which the committee believe exists about the long term well being of children born to such arrangements and the lack of research in this regard*" - The effect of the negative decision is to prevent children from being born who can then be the subject of research. The need for research is a valid point but if taken as a basis for refusing ethical approval, then almost all new procedures would have to be turned down because their long term effects would be unknown. It might be added that research which has been done on IVF children does not suggest that there are any general untoward consequences. Furthermore, the child may be extremely grateful that the gift of life was enabled by the willingness of the birth mother to carry through the pregnancy.

- "*The uncertainty of the effects that such an arrangement may have on relationships although the committee recognised that in some cultures this type of arrangement may have more general acceptance than others*" - The qualification is a significant one, but that aside, the Committee has not explained what its doubts are. On the face of it, a child born through IVF compassionate surrogacy in the circumstances of the application before the Committee will be brought up by the genetic parents. The likely scenario is that the child will be adopted. The birth mother, as a relative or friend of the family, is likely to be a part of the child's life.

- "*The potential for exploitation of women and the ambiguity of payments in relation to surrogacy*" - We have already discussed these points in the previous section. They appear to be generalisations rather than reasons applying to the specific application. Any doubts about exploitation of the women (and the genetic father?) who were the subject of the application and any question about monetary payments (which as noted above are not necessarily illegal and may in some instances be a legal or moral obligation) should have been clarified with the applicants.

- "*The need for indemnity cover for women particularly in relation to the drugs used and for the risks involved to be adequately addressed*" - This is an appropriate concern, but it is not a reason for declining the

application. It is a matter for discussion with the applicants and possibly an enquiry to the Accident Rehabilitation and Compensation Insurance Corporation. There is no procedure laid down for appealing against the decisions of INECART, although those decisions might be subject to judicial review and in the future structure there may be a second opinion given by the National Advisory Committee on Health and Disability Service Ethics. The decision of INECART was a final one but the Committee's precise words were that ethical approval could not be granted "at this time". We suggest therefore that the appropriate course of action is for providers to submit a new application to the reconstituted ART ethics committee.

6. OPTIONS FOR THE FUTURE

There are many different models throughout the world for dealing with surrogacy. There are few consistent patterns. We highlight the main options, bearing in mind that there are many possible variations.

Modification of the Present Situation

One option is to allow the present situation to continue, which means that the courts and ethics committees will address issues as they arise. We envision ethical approval being given under strict guidelines. As in Britain, we would not expect approval to be granted unless there are genuine medical reasons. Social reasons for surrogacy would not be enough. The British experience suggests that ethical approval would not become routine. Where an ethics committee is in doubt about an overall policy issue affecting an application made to it, the Council for Assisted Human Reproduction could be consulted.

The advantages of this option are that it allows law and practice to develop incrementally as the need arises. Surrogacy within the professional clinics is more likely to be adequately controlled, with appropriate safeguards applying. Proper record keeping is important as are high safety standards. Recourse to back-street operations and procreative tourism may be reduced.

There are some disadvantages to this model. It is not clear that there is anything to stop surrogacy which has not received ethical approval occurring outside the accredited clinics. We have serious reservations whether the law should try to control people who engage in sexual intercourse even if this is part of a surrogacy deal. But we are concerned that others may attempt to provide a surrogacy service without the safeguards that the public interest demands. Where the provider is a member of the medical profession, we expect that professional forces could be brought into play (although, see our chapter on "*Regulation*" for some doubts in this regard). Providers outside the medical profession would not be under such pressures. Likewise, there would appear to be nothing to stop commercial entrepreneurs making a bid for a "market share".

As a bare minimum, the Council on Assisted Human Reproduction should be asked to monitor activities in New Zealand and bring to the attention of the Government any concerns that unethical surrogacy is taking place. If such activity should happen in this country on other than a negligible basis, the Council may need to advise the Government to introduce legislation controlling surrogacy. In the meantime, our recommendations on tightening the professional control over ART should also affect surrogacy. (See "*Regulation*" chapter) If those recommendations are accepted, health professionals will have to comply with their profession's requirements for ethical approval, accreditation and record-keeping. Non-medical entrepreneurs will not be allowed to operate.

Formal Provision for Surrogacy

Surrogacy could be formally sanctioned by various different kinds of schemes. One approach would be for it be approved in each case by a court, not unlike the US Uniform Act. Alternatively, surrogacy agencies could be licensed either by the Ministry of Health or some other agency. Coupled with such a licensing scheme would be a ban on other forms of surrogacy occurring outside licensed agencies.

The appeal of this model is that surrogacy can be effectively provided but also controlled. The procedures can be scrutinised by appropriate authorities and the interests of the parties scanned.

It is highly unlikely however that the New Zealand public are prepared to embark on what would be a controversial approach to surrogacy. Because of the polarised views that are expressed, to adopt a model which appears to promote surrogacy and smooth the path for its use would be unwise. It is also not clear that the New Zealand situation demands the establishment of a system such as the one under consideration. Much can be achieved and much safeguarded without licensing agencies in this way. Further, the scheme is dependent upon surrogacy contracts being entered into and given effect to. How this would sit with the paramountcy of the welfare of the child is not entirely clear.

Total Ban on Surrogacy

Surrogacy could be made a criminal offence for all or some of those who participate in it - commissioning couple, surrogate, intermediaries, professionals. One of the most extreme examples of this approach is found in the Queensland Surrogacy Parenthood Act 1988. This Act applies to all kinds of surrogacy, whether assisted means or sexual intercourse are used, whether there is a formal or informal arrangement between the parties, and whether there is any payment or reward or not. The Act criminalises advertising, making payments and entering into or offering to enter into "*a prescribed contract*". Imprisonment for three years is possible.

While such a scheme is a clear statement of legislative policy, it is an enormous intrusion into individual liberties and may well capture traditional cultural practices as well. The question of what happens to the child arises. If all the parties are imprisoned, the child is left orphaned. This is hardly in the best interests of the child. Whether such legislation will stop surrogacy is doubtful. It is probably more likely to push surrogacy underground or drive parties to seek remedies in other jurisdictions.

Statutory Provision that Surrogacy Agreements are Void

Several jurisdictions have passed laws which declare surrogacy agreements void or unenforceable or both. An example is section 6 of the Tasmanian Surrogacy Contracts Act 1993:

> *A surrogacy contract is void and unenforceable wherever the contract is made and whatever law may be the proper law of the contract.*

The principal advantage of such a provision is to clarify a point of uncertain law. However, whether it is necessary or desirable in New Zealand to legislate in this way is a matter of debate. As discussed above, a surrogacy arrangement would not deprive the courts of their obligation to apply the paramountcy of the welfare of the child test to disputed cases. Further, assuming that arrangements are void and unenforceable, this still leaves open the question of what happens to the party who has suffered some detriment in reliance on promises made by another party. The law of restitution and quasi-contract may well provide relief despite the statutory provision.

Advertising Ban

Various jurisdictions ban advertising, whether by commissioning couples, surrogates or intermediaries. Under New Zealand law, advertising would be illegal if it breached section 26 of the Adoption Act 1955, but this applies to advertising which mentions the adoption of a child. Other forms of advertising are apparently within the law, so long as they do not breach general legislation such as the Fair Trading Act.

Attitudes to advertising will tend to mirror attitudes to surrogacy in general. Supporters will argue that advertising, especially by those who are able to offer professional assistance, will lead to simpler and safer procedures. Opponents will argue that advertising enhances the spread of surrogacy and will lead to its greater commercialisation.

Advertising does not appear to be widespread in New Zealand at the present time. There is therefore no pressing need to formulate policy on the matter, although there are benefits in being proactive. We suggest that the situation be monitored by the proposed Council on Assisted Human Reproduction.

Banning Commercial Agencies

The approach of the United Kingdom Surrogacy Arrangements Act 1985 is to not to stop all surrogacy nor to punish the individuals who participate in surrogacy arrangements, but rather to stop agencies from operating surrogacy businesses. The target is not the professional clinics but other intermediaries who aim to make money by putting potential surrogates in touch with couples who desire to use a surrogate. Despite the 1985 Act, surrogacy agencies do exist in the United Kingdom and are set up in such a way that they fall just within the law. There are no moves to close these agencies down. The aims and drafting of any such legislation must therefore be carefully worked through.

Many would doubtless find such surrogacy businesses distasteful, and the risks of exploitation and "*commodification*" of the child are highest when surrogacy entrepreneurs are active. While we are aware of visits of overseas middle men over the past decade, we have not received evidence that commercialism as described is well established within New Zealand. In our view, the need for legislation should be monitored by the proposed Council on Assisted Human Reproduction.

Amend the Adoption Laws

As discussed above, whenever there has been a surrogacy arrangement involving assisted means, the commissioning couple's relationship with the child will usually need to be secured by an adoption order. Some may see this process as cumbersome and an unnecessary burden for the child if an adoption order is not granted. The argument for a simpler procedure of establishing legal parenthood is stronger where the child is the genetic child of the commissioning couple. Section 30 of the United Kingdom Human Fertilisation and Embryology Act 1990, under which a court can make an order that a child born through surrogacy is to be treated as the legal child of the commissioning couple, may provide a model. It is noteworthy that the Supreme Court of California in *Johnson v Calvert* 851 P 2d 776 (1993), in the absence of equivalent legislation to our Status of Children Amendment Act 1987, held that the genetic parents, ie the commissioning couple, were the legal parents of the child.

If surrogacy became a commonly accepted practice, we consider that some review of the law in this area might be necessary. However under current circumstances, it is our view that the present law functions satisfactorily for the few cases which arise.

7. SUMMARY

We have pointed out that there is a spectrum of surrogacy arrangements. At one end, we have concerns about profit-making and "*brokering*" but believe they can be controlled and monitored under our overall regulatory framework (see the

"*Regulation*" chapter). At the other end of the spectrum, we see no overwhelming objections to IVF compassionate surrogacy. No rules should be developed, whether statutory, ethical or codes of practice, which prohibit ordinary sexual relations or whangai, or which place in jeopardy the prospect of a surrogate mother's playing a part in the offspring's life or the offspring's right to information about genetic origins. There should be transparency and accountability in surrogacy. Openness rather than secrecy is to be encouraged.

SUMMARY OF OPTIONS

Chapter 2

1 There is significant evidence relating to several factors which contribute to infertility in our society. Because of the distress infertility causes, efforts should be made to address these risk factors.

Chapter 5

2 The work of the National Ethics Committee on Assisted Reproductive Technologies can be improved in ways detailed in the report.

3 The Royal New Zealand College of Obstetricians and Gynaecologists should be asked to take the initiative in preparing a New Zealand supplement for the Reproductive Technologies Accreditation Committee's guidelines.

4 The revised Medical Practitioners Act should contain provisions for greater professional control of those engaged in assisted reproduction, including power for the Medical Council to create a vocational register and making specialists subject to disciplinary powers. The effect of these changes should be to ensure that all ART providers are accredited and subject to ethics committee scrutiny for new treatments and protocols.

5 The Medical Practitioners Act should contain a provision that nobody can practise assisted reproduction or set up an agency or business associated with assisted reproduction unless they come within the provisions of the Act. The aim is to prevent unqualified persons operating without professional safeguards.

6 We recommend that the following be made unlawful by being included in legislation at the next appropriate time: cloning, animal/human hybrids, implantation of human and animal embryos in the opposite species, and the supply of gametes and embryos for valuable consideration (other than nominal travel fees).

7 Given the advantages of the RTAC accreditation system, we see no need for legislation to establish a separate New Zealand licensing scheme for assisted reproduction providers.

8 We recommend the establishment of an advisory and overseeing body, to be called the Council on Assisted Human Reproduction, with the detailed functions and constitution as set out in the report. We believe that the

Council can be created without the need for legislation, but a statutory body would have the mana of parliamentary endorsement.

Chapter 6

9 Medical insurers should adjust their practices to ensure that they comply with the Human Rights Act 1993.

10 Assisted reproduction providers should alter their practices and policies to ensure that they comply with the Human Rights Act.

11 Guidelines on donor selection and non-discriminatory service provision (with reference in particular to marital status, sexual orientation, age, race and disability) should be prepared by the Human Rights Commission and the Council on Assisted Human Reproduction.

12 Providers should consider the option of making an application to the Complaints Review Tribunal for an exemption under section 97 of the Human Rights Act if they consider they have a "genuine justification".

13 We recommend that section 151(2) of the Human Rights Act be amended to make it clear that there is no difference in our anti-discrimination laws between public and private providers.

14 The Government may consider the option of incorporating a providers' conscience clause into the law, but we caution against amending the Human Rights Act so that assisted reproduction is treated differently from the rest of the community.

15 We consider that most of the concerns which have been expressed about the effects of the Human Rights Act, while meriting further public debate and needing to be monitored by the Council on Assisted Human Reproduction, can be handled within the existing legislative scheme, either by showing that the basis for discrimination was not unlawful or by use of section 97.

Chapter 7

16 We believe that a modified status quo arrangement for the funding of Infertility Services would provide a system which would continue to assist infertile couples while recognising the fiscal constraints of the health sector. We recognise that a comprehensive review of core health and disability support services is being conducted by the Core Health and Disability Support Services Committee.

Chapter 8

17 The Minister should invite the Privacy Commissioner to produce a special code under the Privacy Act to ensure that donation of gametes and embryos will in future be on the basis that the donor is identifiable to the offspring. The code should incorporate procedures for endeavouring to obtain from past donors their consent to identification. The rights of donors to obtain information about offspring should also be included. The Privacy Commissioner must have sufficient funding to carry out this task.

18 If the Government considers that past donors should be identifiable without their consent, legislation will be required.

19 There must be a clear duty on providers to keep information about donation and subsequent births. We believe that this will be fully covered by professional and RTAC obligations if our recommendations for enhancing professional control are accepted (chapter 5, recommendations 4 and 5). However the Government should consider spelling out the duty in the Medical Practitioners Act or Health Act. Other options such as the Consumers' Rights Code are referred to in the report.

20 The Government should give serious consideration to the centralised collection of records on donation of gametes and embryos.

Chapter 9

21 In general, the power to decide what should happen to gametes and embryos should rest with the gamete providers. Legislation should not be necessary for this, so long as clinics ensure that consumers indicate to which courses of action they consent.

22 The Council on Assisted Human Reproduction should consider the preparation of a code on the use and disposal of gametes and embryos.

Chapter 10

23 Certain research should be prohibited by statute (see chapter 5, recommendation 6).

24 We consider that there are sufficient safeguards already in place (the Health Research Council, the National Ethics Committee on Assisted Reproductive Technologies and the proposed Council on Assisted Human Reproduction) to ensure that unacceptable research on embryos does not take place.

25 Research into the psychological, sociological and other aspects of assisted reproduction should be fostered.

Chapter 11

26 We disagree with the decision of the Interim National Ethics Committee on Assisted Reproductive Technologies to deny ethical approval to IVF compassionate surrogacy and urge a new application be made to the reconstituted National Committee.

27 We consider that our recommendations for professional control of assisted reproduction providers (chapter 5, recommendations 4 and 5 above), along with the role of ethics committees, should ensure that commercial entrepreneurs and unqualified people do not engage in surrogacy businesses in this country.

28 Surrogacy, especially so-called commercial surrogacy and surrogacy advertising, should be monitored by the Council on Assisted Human Reproduction.

29 Apart from the proposed changes to the Medical Practitioners Act, no criminal offences in relation to surrogacy should be created. Policy in this area should discourage underground activity and the need to resort to overseas agencies. Appropriate record keeping, the freedom to continue cultural practices such as whangai and the right to know genetic origins must influence the development of policy in relation to surrogacy.

SELECTED BIBLIOGRAPHY

BOOKS

Bioethics Research Centre *Biotechnology Revisited Ethical and Legal Issues in the Application of Biotechnology to Medical Practice* (1991)

Bioethics Research Centre *Proceedings of the International Seminar on Bioethics 1993* (1994)

R Blank *Fertility Control : New Techniques, New Policy Issues* (1991)

R Blank *Regulating Reproduction* (1990)

M Brazier *Medicine, Patients and the Law* (2 ed 1992)

A Campbell, G Gillett and G Jones *Practical Medical Ethics* (1992)

M Charlesworth *Bioethics in a Liberal Society* (1993)

D Cusine *New Reproductive Techniques A Legal Perspective* (1988)

G Douglas *Law, Fertility and Reproduction* (1991)

S Downie *Baby Making The Technology and Ethics* (1988)

A Dyson and J Harris (eds) *Ethics and Biotechnology* (1994)

J Eekelaar and P Sarcevic *Parenthood in Modern Society Legal and Social Issues for the Twenty-First Century* (1993)

M Freeman (ed) *Medicine, Ethics and the Law* (1988)

Fishel and Symonds (ed) *In Vitro Fertilisation Past - Present - Future*

J Harris *Wonderwoman and Superman* (1993)

Albert R Jonsen *The New Medicine and The Old Ethics*

A Kimbrell *The Human Body Shop* (1993)

D Lee and D Morgan (eds) *Birthrights: Law and Ethics at the Beginnings of Life* (1989)

S Lee *Law and Morals Warnock, Gillick and Beyond* (1986)

S McLean (ed) *Law Reform and Human Reproduction* (1992)

S McLean (ed) *Legal Issues in Human Reproduction* (1989)

D Morgan and R Lee Blackstone's *Guide to the Human Fertilisaton and Embryology Act 1990 Abortion and Embryo Research, the New Law* (1991)

T Shannon and L Cahill *Religion and Artificial Reproduction* (1988)

P Singer *Practical Ethics* (1993)

P Singer et al *Embryo Experimentation Ethical, Legal and Social Issues* (1990)

M Stanworth (ed) *Reproductive Technologies Gender, Motherhood and Medicine* (1987)

B Steinbock *Life Before Birth The Moral and Legal Status of Embryos and Fetuses* (1992)

CHAPTERS OF BOOKS

S Anleu "*Reproductive Autonomy: Infertility, Deviance and Conceptive Technology*" in K Petersen *Law and Medicine* (1993)

B Bennett "*Gamete Donation, Reproductive Technology and the Law*" in K Petersen *Law and Medicine* (1993)

J Caldwell and K Daniels "*Assisted Reproduction and the Law: Implications for Social Policy*" in Henaghan and Atkin *Family Law Policy in New Zealand* (1992)

A Grubb "*The Legal Status if the Frozen Human Embryo*" in A Grubb (ed) *Challenges in Medical Care* (1992)

J Habgood "*Legislative Criteria: The Human Fertilisation adn Embryology Bill*" in A Grubb (ed) *Challenges in Medical Care* (1992)

D Morgan and L Nielsen "*Dangerous Liaisons? Law, Technology, Reproduction and European Ethics*" in McVeigh and Wheeler *Law, Health and Medical Regulation* (1992)

ARTICLES

WR Atkin "*Medico-Legal Implications of Assisted Reproductive Technologies*" (1994) 1 Butterworths Family Law Journal 90

E Bernat "*Between Rationality and Metaphysics: The Legal Regulation of Assisted Reproduction in Germany, Austria and Switzerland - A Comparative Analysis*" (1993) 12 Medicine and Law 493

E Bernat "*Towards a New Legal Regulation of Medically Assisted Reproduction: The Austrian Approach*" (1992) 11 Medicine and Law 547

E Bernat and E Vranes "*Reproductive Health Care Policies around the World The Austrian Act on Procreative Medicine: Scope, Impacts, and Inconsistencies*" Journal of Assisted Reproduction and Genetics Vol 10, No 7 1993, p 449

K Daniels "*Psychosocial Factors for Couples Awaiting In Vitro Fertilization*" Social Work in Health Care, 1989, 14, 2, 81-98

K Daniels "*The UK Human Fertilisation and Embryo Authority - One Year On*" The Fertility Society of Australia Newsletter, November 1992, 25, 4-5

K Daniels "*Infertility Counselling : The Need for a Psychosocial Perspective*" British Journal of Social Work (1993), 23,501-515

K Daniels and K Taylor "*Formulating Selection Policies for Assisted Reproduction*" Forthcoming Social Science and Medicine UK

K Daniels "*Surrogacy : Issues and Implications for Society*" 1988 Conference Papers, New Zealand Law Conference, 39-42

K Daniels and K Taylor "*The Private Troubles and Public Issues*" Community Mental Health in New Zealand, 1991, 6, 2, 28-50

K Daniels "*Artificial Insemination Using Donor Semen and the Issues of Secrecy : The Views of Donors and Recipient Couples*" Social Science and Medicine, 1988, 27, 4, 377-383

K Daniels *New Birth Technologies* Guest Editorial, Mental Health News 1987 (July) 3-4

K Daniels and K Taylor "*Secrecy and Openness in Donor Insemination*" Politics and Life Sciences August 1993, p 155 and several other articles by other authors forming part of an "*International Roundtable Article*"

E Deutsch "*Foetus Protection in Germany: The Foetus Protection Act of 13 December 1990*" (1993) 12 Medicine and Law 535

G Douglas "*The Human Fertilisation and Embryology Act*" [1991] Family Law 110

A Eser "*The Legal Status of the Embryo in Comparative Perspective*" (1992) 11 Medicine and Law 579

Fertility and Sterility Vol. 51; 4, pp. 571-577

Gillett W (1988) "*Management of Infertility : A Changing Perspective*" NZ Med J 102 (868):248-251

S Gomombok and R Cook "*A Survey of Semen Donation: phase I - the view of UK Licensed Centres*" Human Reproduction vol 9 no 5 p 882

E Haimes "*Secrecy: What Can Artificial Reproduction Learn from Adoption?*" (1988) 2 International Journal of Law and the Family 46

Hull et al (1986) "*Population Study of Causes Treatment Outcome of Infertility*" Br Med J 1986 291:1693-7

H Jones "*The Status of Regulation of Assisted Reproductive Technology in the United States*" Journal of Assisted Reproduction and Genetics Vol 10, No 5 1993, p 331

C Miall "*The Regulation of Reproduction: The Relevance of Public Opinion for Legislative Policy Formation*" (1993) 7 International Journal of Law and the Family 18

D Morgan and E Bernat "*The Reproductive Waltz: The Austrian Act on Procreative Medicine 1992*" [1992] Journal of Social Welfare and Family Law 420

J Neville Turner "*Review of the Adoption Information Act 1990 (NSW), July 1992*" (1993) 19 Monash University Law Review 343

New Zealand Infertility Society Inc *Newsletters* (March 1990 - October 1991) 1(1)(-2)(3) cited in Brander See (3)

K O'Donovan "*A Right to Know One's Genetic Parentage?*" (1988) 2 International Journal of Law and the Family 27

Paul C et al (1988) "*Contraceptive Practise in New Zealand*" NZ Med J 1988; 101:809-13

Peek J et al (1990) "*Prevelance of chlamydia antibodies in women with tubal disease : impact of chlamydia trachomatis on demand for invitro fertilisation*" NZ Med J 103 (884) 63-65

D Pretorious "*Rights to Gametes, Zygotes and Embryos in Storage*" (1993) 12 Medicine and Law 616

A Purdie et al "*Identifiable Semen Donors - Attitudes of Donor and Recipient Couples*" New Zealand Medical Journal 1992; 105:27

C Rotherham "*Surrogate motherhood in New Zealand: A Survey of Existing Law and an Examination of Options for Reform*" (1991) 7 Otago Law Review 426

H Swanson "*Donor Anonymity in Artificial Insemination: Is it Still Necessary?*" (1993) 27 Columbia Journal of Law and Social Problems 151

G Stewart "*Adoption and Surrogacy in New Zealand*" (1991) 21 VUWLR 131

W Wadlington "*Artifical Conception: The Challenge for Family Law*" (1983) 69 Virginia Law Review 465

W Wadlington "*Contracts to Bear a Child: The Mixed Legislative Signals*" (1992-93) 29 Idaho Law Review 383

CASES

Case No 22991 Post Office Bank Ltd (1989) 9th Compendium of Case Notes of the Ombudsman 37

Davis v Davis 842 SW 2d 588 (1992)

Del Zio v Columbia Presbyterian Medical Centre (Unreported, 14 Nov 1978, New York federal district court)

Johnson v Calvert 851 P 2d 776 (1993)

Moore v Regents of the University of California 793 P 2d 479 (1990)

N v N [1990] NZFLR 188

Parpalaix v CECOS (1984) Tribunal de Grand Instance de Creteil

Re an adoption application (surrogacy) [1987] 2 All ER 826

Re P (adoption: surrogacy) [1990] NZFLR 385 (also reported as Re *Adoption of C* (1990) 7 FRNZ 231)

Wall v Livingstone and Roborgh (1982) 1 NZFLR 417

York v Jones 717 F Supp 421 (1989)

REPORTS AND DISCUSSION PAPERS

New South Wales Law Reform Commission *Artificial conception - discussion paper 1 - human artificial insemination - November 1984*

New South Wales Law Reform Commission *Artificial conception - report - human artificial insemination - 1986*

New South Wales Law Reform Commission *Artificial conception - discussion paper 2 - in vitro fertilisation* - July 1987

New South Wales Law Reform Commission *Artificial conception - report - in vitro fertilisation* - July 1988

New South Wales Law Reform Commission *Artificial conception - discussion paper 3 - surrogate motherhood* - August 1988

New South Wales Law Reform Commission *Artificial conception - report - surrogate motherhood* - December 1988 (JDL)

Board for Social Responsibility *Personal Origins, Report of a Working Party on Human Fertilisation and Embryology* (1985)

Committee to consider the social, ethical and legal issues arising from in vitro fertilisation - Victoria

- Interim Report - September 1982
- Issues paper on donor gametes in IVF - April 1983
- Report on donor gametes in IVF - August 1983
- Report on the disposition of embryos produced by in vitro fertilisation - August 1984

Department of Health and Social Security "*Report of the Committee of Inquiry into Human Fertilisation and Embryology*" (1984, "the Warnock Report")

Family Law Council, *Creating children - a uniform approach to the law and practice of reproductive technology in Australia* - July 1985, Australia

Human Fertilisation and Embryology Authority "*Sex Selection Public Consultation Document*" (1992)

Human Fertilisation and Embryology Authority "*Donated Ovarian Tissue in Embryo Research and Assisted Conception*" (1994)

Department of Health *Infertility - a review of the literature on prevalence, causes, treatment and prevention* (1991/1992, New Zealand)

Law Reform Commission of Canada "*Medically Assisted Procreation*" (Working Paper 65, 1992)

Department of Justice *New Birth Technologies - an issues paper on AID, IVF, and surrogate motherhood* (March 1985, New Zealand)

Department of Justice *New Birth Technologies - a summary of submissions received on the issues paper* (December 1986, New Zealand)

Mosher WD, Pratt WF (1990) "*Fecundity and Infertility in the United States,* 1965-88. Advance data (192) from *Vital and Health Statistics* of the National Centre of Health Statistics

Report on the special committee appointed by the Queensland Government to inquire into the laws relating to artificial insemination, in vitro fertilisation and other related matters (March 1984, Queensland)

Report on the working party on in vitro fertilisation and artificial insemination by donor (January 1984, South Australia)

Royal Commission on New Reproductive Technologies "*Proceed with Care Final Report of the Royal Commission*" (Canada, 1993) and various preliminary discussion papers

World Health Organisation (1975) "*The epidemiology of infertility*". Report of a WHO Scientific Group Technical Report Series 582. Geneva WHO cited in Brander P (1991) Infertility - *A review of the literature on prevalence, causes treatment and prevention. Discussion paper 17 Department of Health, Wellington*

World Health Organsiation (1980) "*Manual on the Investigation and Diagnosis of the Infertile Couple* Geneva WHO

OTHER DOCUMENTS

A Campbell "*The Rights to Parent*" (Paper presented at the NZIS Conference 1993)

K Daniels and P T Tau "*Maori Patients Seeking Donor Insemination: Issues and Implications*"

Human Fertilisation and Embryology Authority "*Annual Report 1992*", "*Annual Report 1993*"

Human Fertilisation and Embryology Authority "*Code of Practice*" (1993)

K Kinjo "*Reproductive Technology in Japan Some Current Issues*" (Paper presented at the 1st World Congress on Family Law and Children's Rights, Sydney, July 1993)

L Nielsen "*Procreative Tourism, Genetic Testing and the Law*" (Paper presented to the 8th World Conference of the International Society of Family Law, Cardiff, June/July 1994)

R Rowland "*Women as Living Laboratories: The Questionable Ethics of In Vitro Fertilization*" (Paper presented at Ethics in Health Care Decisions Conference, Waikato Univerity, February 1993)

N Russ "*Parenthood by Contractual Intent? The Implications of Surrogacy in New Zealand*" (LLM Research Paper, VUW, 1985)

S Smids "*Dispositional Authority over the Frozen Pre-embryo - The Dilemmas that Death, Disagreement and Divorce Present*" (LLM Research Paper VUW 1993)

W Wadlington "*Legislative Responses to Surrogacy Contracting: Recent Experience in the United States*" (Paper presented at the 1st World Congress on Family Law and Children's Rights, Sydney, July 1993)

C Wood "*Artificial Procreation*" (Paper presented at the 1st World Congress on Family Law and Children's Rights, Sydney, July 1993)

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G	Supplementary correspondence from the Human Rights Commission
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APPENDIX A

WRITTEN SUBMISSIONS MADE TO THE MINISTERIAL COMMITTEE ON ASSISTED REPRODUCTIVE TECHNOLOGIES (ART)

Adair, Vivienne	Lecturer in Psychology Education, The University of Auckland
Aickin, Prof D R	Professor of Obstetrics and Gnaecology, the Christchurch School of Medicine
Anglican Church of New Zealand, Social Responsibility Commission	
Archdiocese of Wellington	
Association of Catholic Women	
Auckland Infertility Society Inc	
Baeyertz, Mr John D	Obstetrician and Gynaecologist
Benny, Dr Peter	Senior Lecturer in Obstetrics and Gynaecology, Christchurch School of Medicine
Catholic Women's League (Cathedral Branch)	
Catholic Women's League of New Zealand Inc	
Commissioner for Children	
Core Services Committee	National Advisory Committee on Core Health and Disability Support Services
Daniels, K R	Head of Department, Department of Social Work, University of Canterbury
Davidson, David	Obstetrician & Gynaecologist

Department of Social Welfare, Social Policy Agency	
Dunn, Dr H P	Specialist Obstetrics and Gynaecology
Ellis, Joi and Irwin, Robyn	Independent Counsellors, Fertility Associates Limited
Federation of Women's Health Councils Aoteoroa	
Fentiman, Dr Gary	Obstetrician and Gynaecologist
France, Dr John T	Associate Professor in Steroid Biochemistry Department of Obstetrics and Gynaecology, School of Medicine, The University of Auckland
Gore Catholic Parish Pastoral Council	
Hartfield, Mr Jonathan	Specialist Obstetrician and Gynaecologist
Hayde, Dr Suzanne	Obstetrician and Gynaecologist
Human Life Foundation of New Zealand	
Human Rights Commission	
Hutt Valley Health Corporation Ltd, Maori Co-ordinator Cervical Screening	
Johns, Margaret	Nurse Co-Ordinator IVF Unit, Christchurch Womens Hospital
Joint Methodist Presbyterian Public Questions Committee	
Justice Department	
Legge, Dr Michael	Lecturer in Biochemstry University of Otago
MacLean, Norman E	Obstetrician and Gynaecologist
Medical Council of New Zealand	
Ministry of Health	
Ministry of Women's Affairs	
National Council of Women of New Zealand (Inc)	
National Party - Waikato Divisional Women's Committee	

NZ Catholic Bishops Conference

NZ Doctors for Life

NZ Infertility Society Incorporated

Patients Rights Advocacy Waikato Inc

Patients Rights Inc Christchurch

Pelly, Raymond	Anglican Chaplin Victoria University of Wellington
Richards, Dr Barbara	Obstetrician and Gynaecologist

Royal New Zealand College of Obstetricians and Gynaecologists

Secretary for Justice

Sidey, Dr T K	Senior Gynaecologist

Society for the Protection of the Unborn Child

Society for the Protection of the Unborn Child Inc (National Executive)

Society for the Protection of the Unborn Child (North Otago Branch)

Soroptimist International of Nelson Inc

Southern Regional Health Authority

Southland Infertility Group

Stone, Dr Peter	Acting Head of Department, Senior Lecturer/Consultant in Obstetrics and Gynaecology

Tauranga Women's Health Council

Te Puni Kokiri - Ministry of Maori Development

The Privacy Commissioner

Waikato Womens Health Action Centre

Women for Life National

Women's Electoral Lobby (Waikatio)

Women's Health Action

Women's Division Federated Farmers of New Zealand

Wright, Mr Liam Gynaecologist

In addition to the above personal submissions were received from 26 individuals.

APPENDIX B

ORAL CONSULTATIONS

MINISTERIAL COMMITTEE ON ASSISTED REPRODUCTIVE TECHNOLOGIES (ART)

Adair, Vivenne	Lecturer in Psychology, University of Auckland
ARTEMIS	North Shore Fertility, Auckland
Auckland Infertility Society	
Baird, Mr MAH	President, Royal New Zealand College of Obstetricians and Gynaecologists
Benny, Dr Peter	Christchurch Womens Hospital
Dunedin Infertility Society	
Fertility Associates	Auckland
Fertility Associates	Wellington
Gillett, Mr W R	Senior Lecturer in Obstetrics and Gynaecology, University of Otago
Goldhill, Mrs Flora	Chief Executive, Human Fertilisation and Embryology Authority, London
Greenlane Infertility	Auckland
Hale, Dame Brenda (formerly Brenda Hoggett)	High Court Judge, England
Holmes, Dr Andrew and Edgar, Wendy	Core Services Committee
Interim National Ethics Committee on ART	
Mulgan, Margaret	Chief Human Rights Commissioner
New Zealand Infertility Society	
Polak, Fr Max	Catholic Chaplain, Waikato University
Sidey, Dr T K	Senior Gynaecologist, Dunedin

Slane, Mr B H	Privacy Commissioner
Southland Infertility Group	
Waller, Prof Louis	Monash University, Victoria
Wright, Mr Liam	Gynaecologist, Auckland
Yates, Dianne	MP

APPENDIX C

E TORO NEI NGA KAWAI TAURA TANGATA: THE HUMAN LINKS EXTEND LIKE BRANCHES OF A TREE.

ANALYSIS OF WRITTEN SUBMISSIONS MADE TO MINISTERIAL COMMITTEE ON ASSISTED REPRODUCTIVE TECHNOLOGIES

LORNA DYALL
JOCELYN KEITH

JULY 1994

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WHAT NEW ZEALANDERS WERE ASKED

The Ministerial Committee on Assisted Reproductive Technologies stated that they wanted to hear the views of people in our community about the issues raised in the short issues paper which they distributed and any others considered relevant to assisted reproductive technologies (ART). They regarded the paper as only a starting point and believed that further issues would emerge during the consultation and with future developments and thinking. They acknowledged previous work, especially that of the Interdepartmental Monitoring Committee on Assisted Reproductive Technologies (IMCART), and various publications of the Law Reform Division of the Department of Justice.

The terms of reference were to:

(a) find out what is happening in the field of ART in New Zealand;
(b) talk to interested groups and individuals to get their views on what is happening here and what would happen here;
(c) gather information, from the literature available in New Zealand, about developments in other countries;
(d) report to the Minister of Justice by 30 April 1994.

The major sections in the short issues paper were:

Background

This listed the interventions now commonly available and referred to as ART, including

- in-vitro fertilisation (IVF) and embryo transfer (ET)
- gamete intra-fallopian transfer (GIFT)
- donor insemination (DI)
- surrogacy
- pronuclear stage transfer (PROST), etc.
- possible new techniques.

Infertility

- what is infertility
- to what extent does society create expectations about fertility and family which cannot always be fulfilled?

- to what extent is the ability to procreate a natural and deeply felt part of a person's identity and sense of self worth or self-esteem?
- to what extent is the ability to procreate a human right?
- what resources are being, or should be, devoted to the prevention of infertility?

Infertility Services

- should more infertility services be part of the core health services offered through the public health sector?
- should distinctions be drawn between different types of infertility services or different levels when determining core health services
- what accreditation/qualifications should there be for providers of infertility services, especially those involving advanced technology?
- if changes to the accreditation system are made, how can protection from infectious diseases be assured?
- what support services, including counselling, should be available and should they be optional or mandatory?
- should any discrimination be allowed in providing infertility services?
- should providers be able to discriminate on the grounds of marital status, sexual orientation, health status, etc. when selecting donors and recipients?

Commercialisation

- does the issue of commercialisation make a difference to the types of services or procedures offered, e.g. is DI different from surrogacy in this respect?
- does it matter that private services may be available only to those who can afford them?

Law

- should the law, or some other form of regulation, spell out the rules relating to creation, use, storage, disposal, research and ownership of embryos?
- should embryos be created only for transfer and implantation?
- what should happen to "*spare*" embryos?
- should gamete (sperm or egg) providers be entitles to claim possession of embryos?
- how should disputes between gamete providers be resolved?
- how should the law regard surrogacy agreements (whether they are for

financial gain, or pure voluntary or altruistic)?
- should the law treat surrogacy agreements involving ART and those involving sexual intercourse differently?

With respect to regulation:

- should there be regulation of agencies involved in ART?
- are different options appropriate for different forms of ART?
- if there ought to be regulation, what form should it take:
- market forces;
- legislation outlining what is permitted under what conditions;
- legislation banning certain procedures;
- a statutory licensing or monitoring body which licenses providers, sets out, updates codes of practice and monitors quality control;
- professional regulations through the Medical Council and the Royal College of Obstetricians and Gynaecologists;
- control through public sector ethics committees (whether established by statute or not);
- contracts between donors, patients and providers with enforcement through the Courts as with other contracts;
- a combination of various approaches?

With respect to information:

- should a formal system of collection of, storage of and access to information on genetic origins (whakapapa) be established?
- would the information be collected centrally or be the responsibility of providers under professional or other regulations?

- what information would be collected? - would it identify the donor personally or just some general characteristics like iwi etc.
- who would be entitle to access this information and what rules would control its release?
- what are the limits of privacy and confidentiality?
- what would be the sanctions for failure to comply?
- what variety of cultural views need to be considered?

With respect to informed consent:

- should legislation require informed consent by donors recipients and partners?

If so, what matters should this consent cover and how should it be gained?

Ethical considerations

Are there any underlying and fundamental principles which should be taken into account in making decisions on ART?

The Committee was also interested in the range of views that New Zealanders hold about the following:

- the "*right*" to reproduce
- the use of technology to assist human reproduction
- the status to be given to am embryo at different stages of development
- surrogacy
- research on gametes and embryos
- the donation of semen, ova(eggs), and embryos
- how can you assess the best interests of a child at the embryo stage?
- how important is it to know one's genetic origin?
- what rights or interests do the following have - the child or embryo, the donors, the recipients of ART services, the non-genetic birth mother, partners of donors, surrogates and recipients, the wider family and whanau, the service providers, and the general public?
- how should these "*rights*" and "*interests*" be balanced?
- do these rights change at any stage or in any circumstances?

Issues for Tangata Whenua

The following questions were asked in addition to the five principles developed by the Ministry of Maori Affairs, Manatu Maori:

- what other issues are raised for Maori?
- what processes need to be put in place to ensure Maori participation in decision-making?
- what socio-economic, socio-cultural, ethical and services issues are raised by current knowledge of Maori health status?

Future developments

New Zealanders were asked what future developments they envisaged as arising in this area and what steps should be taken in advance to prepare for them.

Service providers wanted answers to the following:

- what is the maximum number of embryos (ova for GIFT) that should be transferred?
- what is the role of diagnostic IVF - i.e. testing the penetrability of an egg with donated sperm?
- on the gradient of research and technology, where does the scientific training fall?
- should the export/import of gametes or embryos be considered?
- is there a grey area between compassionate surrogacy (not paid but expenses covered) and commercial surrogacy (paid a fee plus expenses)?

THE SUBMISSIONS

Almost one hundred written submissions were received by the Ministerial Committee. These varied very considerably, ranging from tiny handwritten notes to substantial research reports. Quite a number of people simply copied to the Committee submissions they had made on previous occasions.

A preliminary breakdown of the sources showed:

- individual public submissions
  22 (2 people made two, one person made three)

- submissions from providers (mostly obstetricians and gynaecologists)
  12 (one person made two)

- statutory organisations
  11 (including the Secretary for Justice, the Ministry of Health, the Ministry of Women's Affairs, the Department of Social Welfare)

- national non-governmental organisations
  15

- regional organisations
  18 (one made two, one made three)

Only one submission was specifically labelled as being personal and confidential.

In addition, the Human Rights Commission also sought public submissions as part of its own submission-making process. They received around 25 submissions, quite a number of which came from organisations who also commented directly to the Ministerial Committee. It would be fair to say that there were some voices missing from the written submissions, especially the

voices of infertile men or homosexual men.

THE ANALYSIS

The process of receiving submissions, analysing them and presenting the views expressed is just as important as the final use to which the information is put. The issues raised by this consultation will continue to be discussed. The process must have integrity if it is to achieve its purpose.

Because of the questions format of the Issues Paper, it should have been possible to use standard quantitative techniques to analyse them and to present New Zealanders' preferences in tables and graphs. Only about one-third of the submissions followed some or all of the format. The other two-thirds addressed a whole variety of issues from a wide range of perspectives and it was simply not possible to analyse them in a quantitative manner without distorting them. A different approach had to be used.

This analysis of the written submissions to the Ministerial Committee is the work of two New Zealand women, one Maori and one non-Maori , who undertook a similar analysis of over 6000 of the submissions made to the Royal Commission on Social Policy in 1988. (See The April Report: Volume III Part One: Future Directions "ME ARO KI TE HA O TE TANGATA: LET THE PEOPLE SPEAK". They describe their way of working as "Nga to hoa aroha", a shared commitment so named by two other collaborators, Sir Apirana Ngata and Sir Peter Buck.

Sir Peter wrote to his great friend:
"*Ma taua ano e wehewehe nga taonga, ma taua e whiriwhiri ke tewhea kete ki tewhea kete. Ma taua ano e raranga he kere hou mo nga taonga kaore e tika whaona ki nga kete tawhito.*"

It is you and I who must separate out the items and sort them into each basket. It is you and I who must weave a new basket for the items which it would be wrong to place in the baskets.

This process uses a "*patterned*" approach. This entails sorting submissions by theme rather then by specific response to each question, and by allowing them to relate to each other. At all stages, the submissions were considered by both researchers. Once enough submissions were sorted to make the pattern clear, all remaining submissions were sorted. There were many linkages. Some submissions belonged in only one "*basket*", others in two, some in all.

THE RESULTS

The voices of the submissions were many and varied. While they were diverse in their style, their message, and their strength, they were surprisingly consistent in their values. Each in its own way sought integrity, integrity of the person, integrity of relationships and integrity of the collective. Integrity for them meant honesty, consistency, a commitment to excellence.

Robert Nozick, in his "*Philosophical Explanations*", develops the notion of "*organic unity*" to describe the difference between the whole and the sum of the parts. This concept of organic unity is very familiar to Maori. In the section of the report of the Royal Commission on Social Policy, entitled "*Nga Tikanga Me Nga Ritenga O Te Ao Maori*" (Standards and foundation of Maori Society), the concept of "*hauora*" (wellbeing) is described. Four cornerstones of wellbeing are explained. These are taha wairua, te taha hinengaro, te taha whanau and te taha tinanga. Although hauora is an individual quality, the wellbeing or the integrity of the person, it is totally dependent on collectively qualities such as whanaunatanga and turangawaewae. In this way hauora is linked to mana, a quality sometimes bestowed collectively but with individual benefits.

Many of the submissions recognised the importance to develop a framework which took account of the Treaty of Waitangi and the perspective of the tangata whenua. There was general agreement that a framework cannot be taken from an overseas model and placed in New Zealand without any adaption.

1. INTEGRITY OF THE INDIVIDUAL; HE AHA TE MEA NUI? HE TANGATA, HE TANGATA.

Respect for human existence and its vulnerability ran throughout the submissions. Life, they said, is important from conception to death (010), new human life is a gift, a unique person, equal in dignity to every other person (105). They spoke of "*personhood*" (012), of what it means to be authentically human (015), and of the dignity and implicit worth of every human being as "*a basic precept of most societies*".

The paramountcy of the child was undoubted. The principle of integrity was applied also to the embryo as well as to the adult persons involved in assisted reproductive technologies - donors and recipients, surrogate mothers. The integrity of those who practice the technology and advance the knowledge in this field was considered under the following section, the integrity of relationships.

1.1 The integrity of the child

"*The child should be at the ethical centre*". (034)

The submissions said that the personality of the child will be founded on a relationship in which she is uncritically loved for her own sake. . . . [T]he development of this bond should be interfered with only for compelling reasons. "*The inability of the mother to look after the infant might be such a reason. The existence of a contractual agreement.*" (003)

This emphasis on the establishment of the child's identity, the knowledge of one's biological and social history, was frequently set within the family context. This was addressed in terms of whakapapa, "*every human being is entitled to knowledge of their biological ancestry*" (017), offspring to know identity of genetic parents (001), the dangers of being dislocated from inherited genetic links(018) and the problems which might await children "*who know they are [different] because of this different kind of origin*" and of the human need for belonging. "*The foundation of his personality on a sense of belonging [to the family circle] remain[s].*"(003)

Any hint of commercialisation of the reproductive process was strongly resisted throughout the submissions but most emphatically in relation to the children themselves.

"*[Considering children] as a commodity is dehumanising and dangerous to wellbeing because of the diminished sense of self*"

"*In an increasingly individualistic materialistic society ,there is a danger that through ART a child will become treated as a commodity, to be created, bought or sold, on the basis that individuals can afford to do so. . . [W]e believe that the wider society has a duty to protect the interests of children and to speak for them.*" (072).

The right to information and the processes for the collection of that information formed the basis of many submissions and a variety of suggestions were made. "*Children born as a result of ART should have access to identifiable donor information. This requires the establishment of a formal system for confidential storage/retrieval of information. . . The provisions of the Adult Adoption Act and the regulations for the National Cervical Cancer Screening Register could be investigated as models [and] the development of a privacy code for ART services.*" (025)

"*Where it comes to the attention of the authorities that a child has been born of a surrogate motherhood arrangement, full records of the child's social/biological parents should be . . . lodged with the relevant Registrar of Births. . .*" (027)

"*I would envisage a key number . . on a birth certificate . . . available to a child and/or donor . . . at a specified age [of the child] ...*" (033)

This was particularly important for Maori.

"*Maori offspring should have access to information about whakapapa, if possible including whanau, hapu and iwi details. Everyone should have access to information about ethnic and/or genetic family origins.*" (032) But it also raised questions about whether iwi would want to hold separate information or whether a kai tiaki group would need to protect Maori data.(032)

Other issues included:

- the welfare (physical and psychological) over time of children born with the assistance of these new technologies
- guardianship
- arrangements for advocacy.

1.2 Integrity of the Embryo

Many submissions wanted some legislative process to protect the integrity of the embryo, which whether the embryo is viable or not, must be respected. (015, see also 018.027,028) and consequently, "*the practice of keeping embryos alive in vivo/ in vitro for experimental or commercial purposes is totally opposed to human dignity*".

There were statements about the status of the embryo:

- the status of the embryo to be recognised at conception (011)
- a fertilised ovum is a microscopic human being even before it is implanted.

Specific issues included:

Storage

- storage/experimentation without immediate prospect of transfer to the womb and the selection and wasting of embryos is all wrong. Some considered that embryos could be kept for 10 years (011), others for longer.

Ownership

> . . . [n]o one has authority to take the life of another person and the same applies to what we have good reason to believe might be a person.
> . . . embryos are not property. They are incapable of being owned either by the biological parents/ social parents/ IVF team but all have obligations

to protect them.(015)

"*Spare embryos should be the property of the commissioning couple . . either for destroying, experimentation or donation [with] the opportunity at predetermined time spaces to renegotiate the status of these embryos.*" *(033)*

- [fertilisation of more embryos than are needed for implantation] introduces an element of selectivity in human reproduction and a notion that lives of some individuals are dispensable commodities.

- all commercial trafficking should be prohibited (018).

Research and Experimentation

Some wanted no research on unborn children at all (010). Others limited it - "*experimentation that is not directly therapeutic, is illicit inside/outside the mother's womb . . . no operations on live embryos unless moral certainty of not causing harm to the child or mother and on condition that the parents give their free and informed consent*" (018).

1.3 The Integrity of the Adults Involved

The main concerns here related to women as donors, recipients, and surrogate mothers.

"*ART contains the potential to exploit women in a number of ways. Women who seek ART often have falsely raised hopes about the efficacy of the procedure. The success . . is frequently exaggerated, and the failures are invisible.*" One submission commented :

"*Intervention/interference with a woman's body through ART gives rise to concerns of abuse [as] an instrument for reproduction/ status of a laboratory.*"

Some singled out women who are childless for special concern. (See further under relationships)

"*The identity of women in particular is inextricably linked with whether she has children. For many women the discovery that they cannot perform one of the fundamental (if not virtually compulsory) acts that her society requires of her, can be shattering.*" (032)

At least one was very clear about the duties of women who had agreed to become surrogate mothers. "*The surrogate mother may behave badly (smoke and drink alcohol) and damage a normal foetus. There needs to be regulations about how she can be*

restrained and how the child and its adoptive parents can be recompensed for the environmental damage caused in utero." (034)

1.3.1. **The Recipients** (See also under relationships)

There were moving and very personal letters from women who had suffered demeaning experiences and who had felt less than whole because of their inability to conceive. Some very evocative poetry and stories were included. Others wanted clarity about the use of the term "*infertile*", some using it to refer to "*people who experience, as problem, the inability to conceive*", others anxious that it should not be used to "*refer to people who have not had children, out of choice of lack of opportunity*". (032)

For some women, access to ART services served to restore that wholeness, even where there was to be no child, it gave them "*a sense of being underway to resolving, one way or another, the debilitating disease.*" (004) They felt that it enabled them to do all that was possible and they were able to get on with the rest of their life in a way that could not have been possible without it.

Counselling throughout the process, was an absolute priority and many women praised existing services for their careful attention.

1.3.2 **Surrogate Mothers**

Not surprisingly, surrogate motherhood attracted a range of comment. Some people were utterly opposed, especially on religious grounds; others had a different view. For example, one submission commented "*Surrogacy is adoption started earlier. ... Surrogacy is not adultery. Adultery is in the heart, not the gametes.*" (034)

Some believed that the difference between "*altruistic*" and "*commercial*" surrogacy was one of degree rather than of kind, believing that "*both offend basic human rights/ values and should not be condoned by society in any way*".

There were those who wanted it banned. "*In essence the case for surrogate motherhood rests on a dubious distinction between women as human beings and women as persons necessarily embodied in a female body, capable of reproduction. . . The latter depersonalises women and . . opens the way for obligations that could turn into coercion.*" (012) Others simply wanted it " *... not to be legalised regardless of method used. Too many potential problems, such of which have already been presented in other countries.*" (031)

There were those who wanted it discouraged and not validated by legislation. (001) In particular they wanted legislation against third party involvement, by "*brokers*" and for payment and advertisement to be illegal.

Others acknowledged that it was not possible to make it illegal (003) and that indeed "*in some cultures, surrogacy was seen differently*" (011), but they wanted contracts to have no legal standing.

There was some consensus that, if surrogacy was to be undertaken, then the legislative provisions should be consistent with adoption legislation and thus acknowledge the role of the birth mother in giving consent to adoption and protect her from risk of exploitation (003).

One submission invoked some agreed Australian guidelines which would make

- surrogacy arrangements void/unenforceable
- an offence to enter into any contract/agreement involving the payment of money/benefits for surrogate motherhood services
- an offence to arrange/agree to arrange surrogacy services or contract to provide technical/professional services to facilitate the creation of a pregnancy
- an offence to publish/cause to be published a statement, advertisement, notice or other document to the effect that a person is willing to act as a surrogate or is seeking a woman who is willing to fulfil this role, or is willing to negotiate with a women in this arrangement.

1.3.3 **The Donors**

Clearly the rising call for identifiable information about donors to be available to ART children has the potential to unsettle some donors, particularly those who have donated semen in the past. At the same time, it was generally intended that donors had no rights vis-a-vis any embryo or child resulting from their donation. "*A sperm provider has no 'rights' to an embryo, nor would an egg provider, so why should they be able to claim 'possession of an embryo'*".

One submission asked whether the donors have any say in who may/may not receive their sperm (this in relation to lesbian parents). (014)

Recommendations in one submission (001) included:

- no mixing of sperm from different donors
- donors to be advised of the sex of the resultant child
- donors to give full and informed consent in situations where future contact might be possible

- a limit to be set on the number of offspring (001)

1.4 **Integrity of the Providers, Including Research Scientists** (see also below under relationships)

For many people, integrity meant a commitment to honesty and excellence , to high standards of professional and ethical conduct. There has always been a fear of a "*mad scientist*" who pursues an idea relentlessly in search of a "*brave new world*".

One submission said "*Once you begin, where do you stop? It is not possible to journey safely ...*" (010) Another commented that secrecy can be a "*cloak for shoddy practice, can reduce the effectiveness of registers, can increase the risk of consanguinity and reduce the benefits of new technology in the future.*"

This concern was extended by some to any form of self-regulation suggesting that it would involve vested interests in continuing expanding research efforts with reducing ethical constraints.

Others believe some ART to be largely experimental with associated risks to women and children, especially because of the drugs involved.

Prenatal screening, especially its potential to be used for gender selection, deserves attention with one submission suggesting that the Royal New Zealand College of Obstetricians and Gynaecologists be asked to "*draw up guidelines for the release of information on the sex of the foetus in relation to proposed termination of pregnancy*". (025)

Emerging issues identified were:

- <u>cloning</u>

"*All cloning of individual persons and all research with the purpose of achieving that object should be banned by the State*". (026)

- <u>biologically engineered living organisms</u>

"*A review of the Patents Act be instituted to clarify the status of [these]*" (026)

- <u>chimera</u>

"*All chimera formation involving human genotypes and all forms of intra-species breeding involving human gametes be made a criminal offence with appropriate penalties*" (026).

- the use of foetal tissue

- developments arising from the human genome project. (027)

2. INTEGRITY OF RELATIONSHIPS : E TORO NEI NGA KAWAI, TAURA TANGATA:

As one submission put it, "*the more human the relationships between people, the better the outcome will be*". (072)

The relationships considered were:

2.1 The Child and Its Parents

"*Human parenthood is not the same as ownership of material goods*". (027)

"*The fundamental values at stake are*

- *the inherent dignity/ equality of all human beings*
- *the special entitlement of children to care and protection*
- *esteem for women and motherhood*
- *the integrity and stability of the family.*"

"*In our view, things are round the wrong way. We believe there should be more scrutiny of fitness to be a parent when it involves deliberately creating a child - than when a woman wishes to prevent the birth of a child she feels she cannot cope with.*" (018)

"*My worry is that there is too much concern with baby-making and not enough with child-caring*".

"*Spare*" embryos to be kept for only one year and only while the parents' relationship remains intact." (001)

2.1.2. The Child and Its Birth Mother

Submissions were very clear about this relationship.

"*There is a strong natural bond between mother and infant. ... [she] has carried, imagined, given birth to, suffered for and held in her arms ... it is hers and a part of her in a way that it cannot be for any other person.*"

"*There is evidence that a womb is not just a sterile incubator and that the [gestational] experiences, physiological and emotional, have an effect on the developing foetus.*" (033)

"*The child is 'given' freely and with love . . [where] such giving and receiving is compatible with the giver's and recipient's values, . . . within family where possible.*"

"*An unacceptable form (of surrogacy) is where the child is a commodity and the mother little more than packaging. It dehumanises both parties and is unsafe for the child short term and long term.*"

"*Surrogacy dislocates the mother and child [relationship]*".

"*An independent advocate for the child is a must for any surrogacy proposal*". (003)

2.1.3 **The Child and Its Whanau**

"*... [C]are is usually shared within a family. ... The child is 'given' by the mother and 'belongs' to the family*". (003)

"*Maori surrogacy has always been an option for childless couples ... The whangai concept (customary Maori adoption) is known to the law.*" (025)

2.1.4 **The Child and Subsequent Generations**

"*Human beings are entitled to know their biological ancestry*" (017)

2.2. **The Professional/Client Relationship**

(Note: Clients could be an infertile couple, donors of gametes, a surrogate mother, a child or a wider family group.) Honesty was a highly prized quality in this relationship, seeking to ensure that the true success rate is taken into account, including the number of treatment cycles and their consequent costs (physical, emotional, financial), the fate of embryos, multiple pregnancies, ectopic pregnancies, spontaneous abortions, induced abortions, perinatal death rates, very low birth weight infants and malformations. (028)

For some people, non-therapeutic intervention is not acceptable. Some submissions maintained that, in spite of the human rights legislation, "*some discrimination is necessary in providing infertility services*".(009)

One described the grounds for this:

"Those who present the best clinical chances of success ... based on current health status. Service rationing should be transparent and consistent. Any form of discrimination on social grounds . . is considered unacceptable." (025)

Several submissions set out issues which should be features of any quality service especially

- a heavy emphasis on counselling;
- that there must be full disclosure of information where perfect lifelong secrecy cannot be guaranteed. (003)
- screen all donors for genetic illness/acquired conditions which could affect the child
- protect recipients from donor-acquired disease e.g. HIV
- not consider two adults of the same gender
- age should be a barrier at both ends of the scale (18-55 for recipients, 18-35 for donors). (?)
- cultural safety for all people and in particular Maori by employing Maori to counsel/advise Maori clients, recruit and support Maori donors(025)

3. PARTICULAR RELATIONSHIPS

3.1 The (Heterosexual) Marriage Relationship

There was a lot of debate about rights of various kinds, in particular the right to procreate. One submission said that *"it is not a right but a privilege to reproduce within the marriage relationship."* (010) while another believed that *"it is a fundamental right of married couples to reproduce."* Another stated that *"Human reproduction belongs to marriage. ... The meaning of sexual actions/ human reproduction is rooted in the meaning of marriage . . as an exclusive relationship"*. (015)

There was concern that when those seeking to conceive a child are not married, it could conflict with the principle of safeguarding the integrity of marriage. (027)

Others cited international rights to *"establish a family"* (see for example, the submission of the Human Rights Commission).

3.2 Lesbian/Homosexual Relationships

Several submissions were made by lesbian or homosexual couples who argued that homosexual people are as diverse as heterosexual people, especially in their capacity to parent. (014) They asked how they were so different from other couples who receive assistance in establishing a family. Some have established

mutual contracts to safeguard their rights and the rights of any children.

Others commented:

"*Single women, lesbians and fertile married women do have the option of getting pregnant the regular way with a fertile man. While this might be considered distasteful by the individuals concerned, it is possible for them to have a child without medical intervention. ... We believe that people seek a medical solution because it allows them to avoid confronting what they are doing. It turns the social act into a medical event, sanitises it, and provides a kind of social sanction for what is otherwise regarded with disapproval by some sections of the community.*" (072)

Some recognised the risks "*for lesbian women whose donors are more likely to be gay/bisexual men, the highest at-risk group for HIV*".(032)

3.3 **Childless Couples**

"*Childlessness can be experienced as a personal tragedy for couples who want a child and ethically appropriate ways of helping them are to be welcomed.*"

"*For people with involuntary subfertility, there is a definite sense of loss of self esteem and worth. This is expressed by the lengths to which some will go to achieve conception.*"(033)

"*We understand the anguish of childless couples, we empathise and applaud their desire for children . . .[but] progressive adoption of ART as a solution to infertility may not serve the interests of women, children or society*". (018)

"*We have listened to the stories of women of the '50s and '60s who were unable to conceive but who were subjected to a great deal of insensitivity by other women who were rearing big families at that time.*" (019)

"*In the '90s, there is a much more liberal attitude to childless couples but many are assumed to be childless by choice when in fact they are infertile, creating great emotional stress. [The] ability to procreate has a deeply felt spiritual dimension and the emotional need is real, one of the fundamental aspects of existence*". (019)

"*There is still great pressure on those who do not have children but those born in the 1970s have a much more liberal attitude. Maybe that is where the turnaround in thinking will come from.*"

"*It is realistic to accept that some couples will have to accept permanent childlessness. Society must accept this and change its attitudes so that a person does not feel that his/her self worth and esteem is based on producing children.*" (016)

One submission sought to explain it this way:

"Expectations about fertility/family and ideas about the ability to procreate are socially constructed values that are shaped by different cultural contexts. Pakeha and Maori society (Maori because it has been irretrievably influenced by the Judeao-Christian values of the coloniser) exerts excessive social pressure to conform to a romantic paternalistic value of the (nuclear) family unit. In more cases than not, this "ideal" is not achieved . . It is their choice to procreate or not that should be a human right." (032)

4. INTEGRITY OF THE COLLECTIVE: KOTAHITANGA EHARA TAKU TOA I TE TOA TAKITAHI ENGARI HE TOA TAKITINI

The whole debate of ART rests upon a balancing of the needs and desires and perceived rights and responsibilities of individuals and those of the collective, of society as a whole. This can be addressed on several levels. This section sets out the way in which New Zealanders sought to establish this balance, especially in the relationship between the State and citizens/ taxpayers, in their written submissions to the Committee.

Submissions have been grouped under the following headings:

4.1.1 The State as Guardian: Kai tiaki

- the responsibility to protect the whole without ignoring the weakest and most vulnerable, in this generation and between generations;

- the maintenance of the ethical integrity of the nation based on collective values and principles, the fabric or korowai which is the basis of the wellbeing of our society.

- the honouring of the Treaty of Waitangi which sets out the relationship between Maori and the Crown and the rights and responsibilities which flow from that commitment.

4.1.2. The State as Lawmaker

Whether there should be legislation or not. If so, what form should this take. What should it cover? For what time period? With what process of monitoring and review? What provision for public input? What process of appeal. The regulatory options open to Parliament range from minimal market direction through guidelines and codes to regulations and finally to statutory banning.

4.1.3. **The State as Tax Collector**

- the efficient use of the tax take to advance the wellbeing of New Zealanders as a whole, including the role of the Core Services Committee in determining the "*core* " of publicly funded health services.

4.1.4. **The State as Guardian: Kai Tiaki**

"*The State has an obligation to uphold human dignity to provide adequate protection for all people in New Zealand, Maori and Pakeha*" (024). The arguments for guardianship by the State were made in terms of

- social standards
- the view over time: outcomes
- establishing the groundwork :arguments about what constitutes infertility
- guiding changing thinking: surrogacy as the "*bureau de change*"
- allocating rights and responsibilities

The Treaty of Waitangi was cited by many as a useful framework for that protection. It was seen as the means by which Maori "*rightfully give expression to their responsibilities, values and expectations*" and by which the Crown has a responsibility to ensure that effect is given to various cultural options in respect to infertility. (086)

4.1.5 **Social Standards**

Many submissions believed that it is essential that every area of our life is governed by fundamental principles (022) and quite a number echoed the belief that there would be "*fewer problems in the field of pro-creation if society would abide by the principles given in the Bible*".

Many submissions referred to the role and nature of ethics committees, most frequently in favour of a national committee. One submission spoke strongly against any continued role for ethics committees (national or regional) in making decisions about ART, saying "*The Lawmaking process is more open and accountable, and provides more opportunities for public discussion and submissions by interested parties. ... There is a real danger that ethics committees will be captured or unduly influenced by interested parties.*" (072)

Any legal framework or policy guidelines in respect of ART was seen as the means to safeguard fundamental rights and values. One submission suggested that this including safeguarding:

- the right to life from conception to death
- the dignity of the person
- the integrity of marriage and the family
- the common good. (027)

Another set of principles advanced as underlying collective decisions regarding ART was:

- informed consent/choice
- privacy of human dignity
- regulation controlling financial gain
- public discussion and informed debate.

Whatever the process, there was public insistence on a process in public control with no prospect the "*new technologies could slide in through the back door as has already happened over the past few years.*" (072) In a very few submissions, this thinking was in the context of the processes governing the introduction of other medical technologies.

4.1.6 **Outcomes**

The public was adamant that any decisions made must protect children born using ART in both the short term and the long term. (023)

The Human Rights Commission concluded from the submissions it received

"*That there is little consensus in the community about what constitutes the optimum environment for raising children*". This was a rather surprising finding given the heavy emphasis throughout these submissions on the need to consider the family environment in which any children resulting from ART were to be brought up, e.g. "*The more human the relationships between people, the better the outcome will be*". (072)

4.1.7 **Defining Infertility**

A consistent definition of "*infertility*" was "*the inability to conceive after on year of unprotected sex between a male and a female*". The comment was made that this is a "*poorly defined term which does not accurately describe the condition of those who seek ART.*" (072)

Some people were quite clear that the definition of infertile could not extend to lesbian or homosexual couples. A single woman, in their opinion, could be considered infertile merely because she is single. They believed that "*a*

heterosexual relationship which exists between a man and a woman is the only relationship which can ever biologically produce a child. Therefore the term "infertility" can only be applied to this relationship." (024)

A different emphasis was obvious in the move to the term "*sub-fertility*" , especially relevant to the new techniques which enhance sperm counts. There was passing reference to the falling fertility rate for Maori women and one submissions urge clear identification of the fertility rate of Maori women in relationship to the decline in the Maori birth rate to ascertain the expected level of demand for ART from Maori.

Others believed, as does the Human Rights Commission, that women should have access to the benefits of ART regardless of their marital status or sexual preference. There is an increased risk for lesbian women whose donors are more likely to be gay/bisexual men, the highest at-risk group for HIV/AIDS. They commented further that lesbian women have frequently been discriminated against in child custody cases. (032)

The balancing was seen in terms of "*reasonable access to the means to procreate. Childlessness should be promoted as a positive way of life and services should be supportive of those for whom ART services are unsuccessful.*" (025)

4.1.8 ***"Rights"***

This term was interpreted in a wide range of ways:

- the ability to procreate is not the same as the right to procreate. (032)
- procreation is not a right but a normal biological expectation when two people set up together to live as a family unit. (033)
- marriage does not confer the right to have a child . . . a child is not an object to which one has a right, nor can he or she be considered as an object of ourselves. (027)
- reproduction is a fundamental human need rather than a right. Art is one way of fulfilling this need. (040)
- the ability to procreate is a fundamental part of our existence. It is [also] a human attribute which society should protect. Procreation is not a basic human right but rather a privilege which carries with it certain responsibilities. (047)

The Human Rights Commission, not surprisingly, made this issue a major focus of its submission. They said "*... examining the issue of access to ART from a rights perspective, it becomes apparent that interested parties may have conflicting rights and consideration must be given to a balancing or prioritisation of these rights. Some New Zealand legislation has given paramountcy to the rights and welfare of children e.g. the Guardianship Act 1968. Some have provided that welfare of the child should be taken*

into consideration along with other factors."

They considered that the Commission had an interest in ART in relation to the anti-discrimination clauses in the new Human Rights Act and stated that fertility treatments fall clearly within the meaning of "*goods, facilities, and services*".
If guidelines are developed which are potentially in breach of the Human Rights Act, they will need to be set in legislation, said the Commission, because "*s.151 of that Act provides that the Human Rights Act is subordinate to other legislation and will not take precedence over any conflicting legislation ... even if in conflict with the anti discrimination provision of the Human Rights Act.*"

By far the vast majority concurred with the belief that "*it is the choice to procreate or not that should be a human right*". (032)

One submission proposed an ethical approach within which medical science must work in order to be socially acceptable:

- do no harm to clients seeking help
- accurate information to be given to clients, particularly with respect to the risks and adverse effects;
- the line between experimentation and therapy is to be clearly made
- principles of caring and empathy are to be paramount
- the integrity of the individual is respected and her wishes considered
- relationships are respected
- there must be a balance between the desire of individuals and the matter of the social group. (018)

The balance between rights and interests was to be "*impartial*". (019)

4.1.9 **Surrogacy**

This was the social issue which attracted the most comment in the submissions. A few followed the discussion document format. Other ranged much more widely. Opinions ranged from "*not at all*" to an acceptance of contractual arrangements. Some made the distinction between altruistic or compassionate surrogacy and commercial surrogacy. others saw no difference.

It obviously represented a challenge to the way in which our society responds to the changing thinking about what constitutes a person, human life and personhood which follows the development of ART.

Those opposed said:

"*A woman should not carry someone else's child*" (020)

"Surrogacy can only be seen as a gross exploitation of womanhood. The use, commercial or otherwise of a woman's ability to conceive or ... to give birth to a child for the purpose of providing offspring for other persons is repugnant". (024)

"Surrogacy contradicts the marriage bond and the dignity of the child brought into the world ... [I]t constitutes a direct attack on motherhood setting up divisions between genetic, gestational and social motherhood." (028)

"Ban surrogacy . . . [I] do not believe that compassionate or commercial surrogacy should be supported." (043)

"Not to be legalised, regardless of method used."

Others were more accepting but urged strict controls:

" . . . recommend that legislation be enacted to:
- *make payment and advertisement for surrogacy illegal and*
- *make surrogacy contracts unenforceable."*

This submission also considered that although the use of ART in surrogacy arrangements should be discouraged. private non-commercial surrogacy arrangements should be allowed so long as the law made it clear that any attempt to coerce a woman to give a child is unacceptable. (040)

"Some regulation is necessary to protect all surrogacy situations. . . This should [include]:

- *the birth mother is the legal mother until she signs consent*
- *where there is potential conflict of interests, the interests of the child should be paramount*
- *no party should be involved in surrogacy for financial gain and*
- *because gametes are donated to the surrogate mother, the commissioning couple and any other gametes should receive the same screening."* (042)

"Surrogacy arrangements should be subject to law. The law should treat surrogacy agreements involving ART differently from those involving sexual intercourse." (034)

This submission included the following observations:

- *"Surrogacy is adoption started early ... There needs to be legal protection for those involved. ... [I] do not consider surrogacy to be adultery. Adultery is in the heart, not the gametes."*

The only submissions which actively supported surrogacy came from Maori who discussed the whangai concept which has "*always been an option for Maori couples... Although ART were not traditionally used, these services could be helpful when dealing with Maori. ...*" (025).

4.2 The State as Lawmaker

Although the discussion document set out the options, it was obvious from many of the submissions that people do not understand the intricacies of regulations, statute law, codes etc. It would be fair to say, however, that the majority want a process based on principles, light-handed, workable and publicly controlled rather than striving for a comprehensive complex piece of legislation which may require constant amendment as thinking and technologies advance.

Equally unclear were the levels of technologies being considered. The Ministry of Women's Affairs set out the three-level structure of service provision which was developed by the NZ Infertility Society:

"*Level 1: Basic fertility evaluation and testing, simple ovulation induction, HSG and laparoscopy . . .*

Level 2: Services involving more complex testing and treatment, some tubal surgery, donor insemination and AIH . . .

Level 3: Services for tubal microsurgery, IVF, GIFT . . . " (052)

In retrospect, it would have been most useful if this or a similar list could have been included in the issues paper as this would have made the task of analysing the public response much easier. It was clear that certain sectors of the general public believe that particular activities should be banned. These included the creation and use of embryos for any purpose other than gestation, even where they may be "*donated*", any commercial activity in relation to reproduction e.g. commercial surrogacy - whether in terms of advertising, payment of fees, "*gifts*" or acting as a "*broker*", or any trade and human tissue (eggs, sperm, foetal tissue).

In addition to legislation to achieve these, they wanted adequate legislation to:

- to establish the principle that persons born of gamete donation have a right to information on biological/genetic origins (whakapapa)
- principles to apply to the collection, storage and access to information for offspring
- that information be collected in a secure central register of some kind
- that the identity of the donor be recorded
- that non-identifying information be accessible to offspring of any age

- that access to non-identifying information be a condition required of the donor in participating in a programme, and further it should
- specify what may be permitted and under what conditions
- set out the functions of the statutory licensing body empowered to accredit providers of ART
- rescind accreditation where service providers fail to meet proper standards
- update codes of practice and monitor quality control
- provides for access to identifying information about the child's biological parents and what rules pertain to release of such information (040)

Specific issues addressed:

a. **Regulation**

"*There should be regulation of agencies*". ... (019)

"*The Government regulates health services by means of occupational regulation. ... In ART, it is the safety concerns of all parties that must be balanced. ... Self regulation has developed in the absence of Government regulation in New Zealand*". (025)

There was extensive public support for a licensing process and the pros and cons of continuing to use the Australian system were widely discussed. Some were suspicious of all forms of self-regulation, others believed that the Australian system, augmented as appropriate with New Zealand members including "*consumer/community group representation*", was effective, and others believed that we need to develop a New Zealand process which is "*culturally responsive*". A particular request was made for the results of this accreditation process to be made publicly available. (041)

b. **Ethical Review**

There was support for a national body for clinics to put a case for advanced technology. treatment, accreditation, with representatives from ethical, legal, religious, cultural and consumer bodies to debate issues as they arise. Others felt strongly that there was no "*continued role for ethics committees (national or regional) in making decisions about ART, believing that the legal process is more open and accountable and provides more opportunities for public discussion*". (072).

c. **Central Storage of Data**

Almost all submissions supported a central register (see for example, 033, 043, 046, 047). Some wanted it maintained "*outside current government departments*"

(046) because they foresaw the dangers of linking personal information as has happened with the Child Support legislation. The submission by the Privacy Commissioner was most helpful in this regard.

d. Informed Consent

The statement that "*individuals using the service should be fully informed of the medical, ethical, legal and financial implications of ART, and understand the commitment they are undertaking*" was reflected in many of the submissions. There were various suggestions about the means, e.g "*in the secondary legislation containing the Code of Health and Disability Services Consumer Rights*". (049) of ART (043) Alongside this was a clear call for advocacy services, especially for any children likely to result from the use of these technologies (see the first section on "*Integrity of the person*").

e. Whakapapa

The statements made in the submission by Manatu Maori were well supported.

f. Donor Identity

The disclosure of this information should be consistent with the provisions for adopted children.

g. Discrimination

Many submissions acknowledged that there will always have to be some form of discrimination but any discrimination must be principled discrimination using publicly known and accepted criteria, based on need not only ability to pay. "*Christian justice demands that all types of services legally allowed be available to the poor in the public health sector*". (034) But the clear message has already been discussed under the headings of "*integrity of the child*" and "*integrity of relationships*", including the relationship of science and service providers to society at large.

One asked the question:

"*[We] believe that the rights of the child are paramount and that there may be occasions where discrimination is necessary to safeguard those rights*". This raises many questions:

- should society decide who should be discriminated against and
- should individual providers decide who should be discriminated against?.

h. **Counselling**

"*Mandatory counselling by a trained counsellor with an interest in infertility is essential before any treatment is embarked upon . . . [and] compulsory follow-up by a member of the team within six months of all treatments.*" (021)

If any decisions are made to allow surrogacy using ART in the "*purest*" sense i.e. where there is no genetic link between the birth mother and the child to proceed, "*the non-genetic non-genetic birth mother requires full information and counselling and the realisation of her responsibilities in the final outcome*". (019)

The submission on behalf of the Secretary for Justice, is a most comprehensive review of the existing situation and makes substantial recommendations about the way forward.

4.3. The State as Tax-Collector

In the discussion document, New Zealanders were asked quite specifically about the inclusion of infertility services in the "*core*" of health services to be offered through the public health sector. Although the discussion document set out the interventions commonly available and referred to as ART, it was unfortunate that a more simple level system, along the lines of that developed by the NZ Infertility Society (see above) was not presented.

4.3.1. The Prevention of Infertility

The support for health education and the prevention of infertility was almost overwhelming.

This was :

a. **General**

"*[P]revention of infertility is a key concern from our perspective, given the ... emphasis on low tech rather than high tech experience. ... Prevention of infertility by educating people as to the consequences and dangers involved in living a promiscuous lifestyle is required.*" (023)

"*Infertility prevention needs to have high priority.*" (033)

"*Treatment of the causes of infertility is part of the national part of traditional health services and should continue to be seen in that light ...*". (027)

"*Services to investigate, support and counsel couples is about all the core health services could sustain at this time economically.*" (019)

"*Greater good will be achieved by seeking to prevent infertility than seeking to provide ART ... Promote chastity ... Encourage young people to safeguard and protect their fertility.*" (027)

"*... like to see as much money as is spent on assisting fertility to be spent on why infertility is preventable, a balanced approach is required.*" (023)

"*Would public dollars be better spent on preventing infertility, preventing adolescent pregnancy or helping disadvantaged mothers develop health lifestyles and parenting skills.*" (023)

b. **In Relation to the Spread of Sexually Transmitted Diseases**:

"*[E]ffort to prevent the spread of STD will always be warranted*". (018)

"*Greater effort should be expended on preventing STDs through the promotion of responsible behaviour.*" (032)

c. **In Relation to Subfertility**

"*Resources should be devoted to the prevention of subfertility.*" (034)

4.3.2. Public Funding of Other Services

Many people accepted that "*services which investigate, support and counsel couples should be part of the core services.*" (043)

Comments here ranged from

"*ART should not be considered as core health services*" (024) to "*ART should receive public funding*" (022). Others were frankly honest "*Out of ignorance, I think ART services should not be part of the core services*" (032).

Others proposed ways forward:

"*All options which are proposed as core health services need to be weighed against each other. ... If public funds are to be used there should be discrimination against the use by people who have become voluntarily sterile. ... If there is evidence that groups of people are likely to benefit either obstetrically or psychologically, ... resources should b targeted in that direction.*" (033).

"*Infertility services should be part of core health services. Sub-fertility is not a fatal disease but its does have its morbidity, both psychologically and physically. . . Distinctions do need to be drawn between different levels. . .*" (034)

"*If infertility services are included as a core service, then they should be included as a whole rather than making individual procedures part of the core.*"

"*The parents of a child born after a period of infertility must experience quality-of-life years which are significantly higher than if they had been deprived of these services. . . the costs of infertility treatments should not be a problem for [individual] couples.*" (065)

A national organisation commented that the majority of its members

"*Felt certain aspects of infertility services should be retained within the public health sector. However there was no unanimity as to where the boundaries should be. Regionalisation of services was favoured with the preferred option being one centre in the South Island and one in the North Island. . . [They] should be encouraged to pursue low-tech intervention as an initial solution.*" (047)

Overall, most people considered that "*spending of public health money for ART cannot be justified until other priorities for core health services are adequately funded ... If Art programmes are to be available through the publicly funded health system then they should be equally available to all regardless of ability to pay for procedures.*" (048)

4.3.3. **The Public/Private Mix**

This topic was approached with great caution. Some people felt that "*the private funding of scientific and technological development could well lead to greater exploitation with less public accountability*" (021). Others stated that "*if the public health service is unable to meet the need for a health service (infertility treatment), then it should be purchased from the private sector*". (021)

The exclusion of infertility services from medical insurance schemes is a cause for concern because it means that ART is "*prohibitively expensive for a large number of infertile people.*" (086)

4.4 International Obligations

The questions surrounding ART and other advanced technologies are not unique to New Zealand. They are being addressed internationally.

Some of the answers will be unique to us, reflecting our value system, our beliefs in families and in scientific endeavour.

Others will be universal answers, arising from international covenants and instruments including the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights, and the Convention on the Rights of the Child, ratified by New Zealand in 1993.

"*Both New Zealand law and international instruments make the interests of the child paramount or decisive vis-a-vis other interests.*" (028)

"*... the ethical principles on which the New Zealand law is based should have reference ... to those embodied in international instruments to which New Zealand is a signatory.*" (028)

5. CONCLUSION

The development of ART makes us think differently about humanity, about ourselves, our relationships to other people, when does a person begin, what responsibilities do I have if I gift or donate an embryo or gamete. It makes us question our values and ethical standards, what research is tolerable and what safeguards could or should be in place to protect this generation and future generations. Andrea Dworkin is reported in one submission as saying:

"*Moral intelligence demands a nearly endless exercise of the ability to make decisions: significant decisions: decisions inside history, not peripheral to it; decisions about the meaning of life; decisions that arise from an acute awareness of one's own mortality*".

Given how different each individual is, and the uniqueness of the relationships that individuals have with each other and collectively, and their world views, it should not be surprising that the submissions showed such great diversity. The submission showed the depth of humanity, the pain of those who are infertile, the strong views of those guided by religious or cultural belief. They also showed a great commonality. They all wanted a secure place for themselves in their own lives and to have a say in shaping the future. There was general agreement of the importance of the family in its widest sense and the links that whanau create from one to another.

Many submissions supported the Universal Declaration of Human Rights which recognises "*the right to found a family, the right to adequate health care, and the right to share in scientific benefits and advancements*". (086) The right to found a family does not give the right to procreate although many submissions recognised this is a fundamental human need. Recognising the importance of founding a family, the majority of submissions supported the collection of information about donors, their identity, and the possibility that their offspring should have the right if they chose, to establish contact. The concept of whakapapa was supported by all, that the interests of the child should take paramount and that there should be some consistency with arrangements made for other children in other circumstances such as those being adopted. There was not strong support for surrogacy, whether compassionate or commercial, but whangai arrangements were seen as enhancing family relationships.

Research, and the acquisition of new knowledge, is also a human imperative. People however should control or influence how research is undertaken and how the information is used. Humanity must drive ART, not the other way round. People wanted safeguards, safe process, just processes, to help them control this new technology.

The safeguards proposed included were:

- establishment of a National Ethics Committee
- a central registry for information
- specific legislation to ban certain procedures e.g. human embryo experimentation
- consistent legislation to ensure all children the same
- monitoring and accreditation of providers by an independent body
- further consultation, especially in relation to new issues e.g. genetic manipulation, germ line research
- focus on the prevention and early detection of infertility as well as health services
- recognition of the Treaty of Waitangi as part of the framework for the development and use of ART services in New Zealand
- focus on people, particularly children and women.

The title of the report of the Canadian Royal Commission on New Reproductive Technologies is "*Proceed with Care*". The submissions to the New Zealand Committee have given the same advice - proceed with care and consider all views.

ART provides a vehicle, a canoe, for progress into the future and a new form of human reproduction. How we use the technology will depend how we value and respect the Te Whare Tangata. This is a concept that recognises the importance of procreation, the sanctity of woman, the whanau and the capacity

to care for the next generation. But we travel carefully. We should not go any faster than we feel comfortable with. We stop and look around from time to time.

Huria te rito o te harakeke
Kei hea te komako e ko
Kii mai ki ahau
He aha te mea nui i te ao
Maku e kii atu
He tangata he tangata he tangata.

THE FERTILITY SOCIETY OF AUSTRALIA

REPRODUCTIVE TECHNOLOGY

ACCREDITATION COMMITTEE

TERMS OF REFERENCE

1. To review applications and re-applications for accreditation to perform assisted reproduction procedures, including IVF, GIFT and related technologies and donor insemination.

2. To formulate and revise guidelines as necessary.

3. To site visit centres at intervals.

4. To monitor compliance with guidelines.

5. To review and advise on information material and forms of consent prepared by centres.

6. To publish -

   lists of accredited centres
   lists of research work being undertaken
   summaries of advances in treatment and research
   alterations to guidelines

   and any other matters considered relevant by the Committee.

THE FERTILITY SOCIETY OF AUSTRALIA

REPRODUCTIVE TECHNOLOGY

ACCREDITATION COMMITTEE

CODE OF PRACTICE FOR UNITS USING IN VITRO FERTILISATION AND RELATED REPRODUCTIVE TECHNOLOGIES

In 1986 the Fertility Society of Australia (FSA) promulgated a series of standards as a guide to the code of practice of IVF and related technologies. The Reproductive Technology Accreditation Committee (RTAC), established by the FSA in 1987 added a series of explanatory notes to many of the original standards drawn up by the FSA. These guidelines are to be observed by those centres involved in IVF and related technologies (hereafter referred to as IVF), as part of the Code of Practice.

It is appreciated that there may be differences in detail between these guidelines and those Acts and associated regulations relevant to IVF which have been proclaimed by some States.

The Code has been revised by RTAC in November 1992.

1. *Staff & Resources*

1.1 The Medical Director of the IVF programme should be a recognised specialist in infertility management. IVF should only be offered within the context of a broad clinical expertise in infertility management.

Responsibility for the conduct of the clinical affairs of the centre should be vested in a specialist medical practitioner (the Medical Director) who has specialised knowledge and skills in the management of infertility.

The Medical Director should have access to other specialist medical, surgical, scientific and nursing personnel who also have skills in the particular reproductive technology that is being carried out.

1.2 Specialist anaesthetist services must be available to the centre which must have access to emergency resuscitation services.

1.3 The centre should have access to ultrasound monitoring facilities on a daily basis. The doctor responsible for ultrasonology should possess a relevant diploma or training in obstetric ultrasound.

1.4 Nursing staff with special training in infertility practice should be responsible for the co-ordination, day-to-day care and comprehensive nursing management of patients at all stages of their IVF treatment (Attachment A).

1.5 Professional counselling should readily be available for all patients attending the centre, particularly in times of stress such as: at initial diagnosis, while awaiting treatment, after a failed treatment cycle, when deciding to stop treatment and after an unsuccessful pregnancy.

Counsellors should be professionally trained and experienced in infertility practice (see Attachment B).

1.6 Successful IVF requires the technical and scientific supervision of suitably qualified reproductive physiologists or biologists to maintain the necessary standards of quality control. Laboratory staff should hold qualifications appropriate to their areas of responsibility.

The centre should have scientific directors who possess the appropriate tertiary qualifications relevant to their area of responsibility, e.g. embryology, biochemistry.

The remaining laboratory staff should possess qualifications and training relevant to their responsibilities. The laboratory staff comprises two groups: embryologists, who are responsible for the preparation of the gametes for fertilisation and for the subsequent culture of the embryos; and biochemists who are responsible for the measurement of those hormones in body fluids that are essential (amongst other things) for the evaluation of follicular development in response to hormonal treatment.

1.7 Centres should arrange relevant training for all staff taking part in specialist scientific, clinical, nursing or counselling activities for which existing formal qualifications are not entirely sufficient. Centres with too few staff to provide adequate training themselves, should make arrangements for staff to be trained where there are such facilities. All staff taking part in specialist activities should also receive regular updating and should be encouraged to attend relevant professional workshops, seminars and conferences.

1.8 The centre must have laboratory facilities for the examination of gametes prior to fertilisation and the embryo after fertilisation. The laboratory should be located in close proximity to the clinical facility so that there is no impediment to the transfer of gametes or embryos between the two facilities. The biochemistry laboratory should be accredited by NATA.

The embryology laboratories should provide the necessary facilities for embryo culture and microscopy under aseptic conditions using no-touch techniques. Ideally, laboratory services should be available seven days per week.

1.9 Backup and emergency clinical facilities for each technique practised should be available at the centre, equivalent to those which are standard practice in other specialties and appropriate to the degree of risk involved.

2. *Patient Services*

2.1 Patients should be made aware, before commencing treatment, of the likely financial, social and medical implications of IVF and related procedures. Patients should be made aware of the availability of patient support groups.

2.2 Informed consent is an integral part of the processes of IVF. It is essential that each institution provides a statement in plain language to inform potential recipients about that particular IVF programme.

An important function in the overall monitoring of the clinical practice of IVF is to ensure that patients are adequately informed so that they are able to consent to any procedure with knowledge and understanding of that procedure. This is best achieved by making sure that the staff are aware of the procedures being used and providing the patients with a plain language statement which the couple can take away and study at their leisure before being asked to give consent to any procedure or set of procedures. The consent form should be simple and as free as possible from complex medical terms or jargon. Subjects to be dealt with in a plain language statement are outlined in Attachment C. A list of the topics that should be dealt with in a consent form is provided in Attachment D.

2.3 Patients should be given the appropriate consent forms prior to the beginning of the first IVF treatment and written consent to all IVF procedures must be obtained prior to beginning any aspect of IVF or related treatment. Patients should be given their own copy of any written consent as their permanent record.

2.4 Information for patients should include comprehensive details about treatment options and the treatment regimen, possible side effects and complications, current clinic success rates and the particular patient's chances of successful treatment. It is the medical practitioner's overall duty and responsibility to ensure that voluntary and informed consent is obtained prior to the commencement of any treatment. The use of written material and audiovisual aids is recommended. Information given should be comprehensible to patients. Special attention may be required for patients for whom English is not a first language. At times the educational background of patients might make it essential for a more detailed explanation than usual. Access to an interpreting service should be available.

2.5 There must be a comprehensive counselling service available so that patients know and understand the likely financial, psychological, social and medical implications that treatment for infertility might have on the subsequent quality of their lives.

2.6 Counselling in reproductive technology programmes should also include at least the provision of relevant information and supportive psychological counselling. In providing information counsellors can be expected to respond to patient questions and to further discuss treatment details provided by medical staff, and any implications of this treatment.

Supportive and psychological counselling should help patients to manage the emotional and personal demands of treatment. This may include follow up contact with patients and the provision of crisis counselling.

If donor gametes are to be used, counselling should include all people concerned: donors and their partners as well as the recipient couples.

External counsellors may be a valuable alternative resource for clinics if patients wish to seek ongoing counselling. Satellite clinics could usefully engage these counsellors although in this case, professional education about the particular clinic's practice would be recommended.

2.7 Centres should so far as practicable maintain an up-to-date list of different types of counselling which are available locally and of organisations which can provide information.

2.8 Centres are encouraged to develop training programmes suitable to their own area to enable all levels of staff in contact with patients to understand the needs of patients.

2.9 Centres should ensure that procedures are in place for investigating complaints. After investigation the results should be made known to the complainants.

3. *Information and Consent*

3.1 Information sheets and booklets must be submitted to RTAC, for perusal and comment. Normally they will be discussed at the time of a site visit but when major alterations are made in the intervals between visits, they should be submitted to RTAC forthwith. (Guidelines for the use of information sheets are set out in Attachment C.)

3.2 Consent forms are intended to be a protection for both patient and professional staff of a centre. They should be in plain language and indicate the extent of treatment requested. They must be approved by RTAC and will be examined at site visits: forms for new procedures or major alterations should be submitted in the intervals between visits. (See Attachment D)

3.3 Before anyone is given treatment (i.e. in vitro fertilisation or treatment using donated gametes) or consents to the use or storage of embryos, or to the donation or storage of gametes, he or she *must* be given "such relevant information as to allow *informed* consent". (See Attachment F: *Guidelines for Storage and Use of Gametes and Embryos*)

4. *Treatment Methods*

4.1 All laboratories which handle human body fluids should apply all practices and procedures as outlined in the Australian National Council of AIDS Bulletin No 3 *Laboratory Safety Guidelines that take account of HIV and other Blood-borne Agents*" (January, 1990) or later. Available from ANCA, GPO Box 9848, Canberra, ACT, 2601.

Note that HIV has been isolated from amongst other such fluids: blood, semen, vaginal secretions, saliva, breast milk, amniotic fluid and urine.

4.2 New laboratory and clinical techniques must be scientifically validated and subject to appropriate ethical sanction prior to their introduction into clinical practice.

4.3 The transport, storage, identification and fate of ova, sperm and embryos must conform to standards required to minimise the chance of accident, loss or confusion relating to the donors' or owners' identification.

4.4 Gametes or embryos of different parental origin should never be mixed so as to confuse the biological parentage of the conceptus.

4.5 Although the aim of IVF is to maximise the chances of pregnancy, consideration must also be given to reducing the risks of multiple pregnancy. No more than three oocytes or embryos should be placed in a woman in any one cycle, except in exceptional circumstances. (See Attachment I)

4.6 All IVF patients should be tested for rubella antibodies and Hepatitis B and C antigens at appropriate intervals. At present there is no requirement to test all routine IVF patients for HIV as there is no perceived uniformity of opinion. However, all patients who are either the recipients or the donors of gametes or embryos should be tested for HIV and the material placed in quarantine for 6 months pending repeat HIV antibody testing.

Additional screening tests such as for thalassaemia and Tay-Sachs disease in appropriate circumstances as recommended by the FSA should also be carried out.

Fresh donor oocytes should not be used in IVF procedures except in special circumstances and then only when the recipient couple have received verbal and written information about the possibility of HIV transmission. It is recommended that donor oocytes treatment normally should involve the cryopreservation and quarantining of the embryos as already stated.

5. *Records*

5.1 A permanent record must be kept of all procedures, identifying the patients, donors and recipients of all gametes involved in fertilisation and embryo formation; the final outcome of any attempted fertilisation; and the final locations of any conceptions formed by IVF pregnancies.

5.2 Record keeping is essential in the conduct of the affairs of the centre. The records should be both clinical and the results of laboratory studies undertaken before, during and after treatment cycles. In the recording and the management of patient information each centre should at all times ensure patient confidentiality.

5.3 Results must be made available to the associated or governing institution and to the National Perinatal Statistics Unit. It is essential that a national data base be maintained to compile and analyse the results of IVF (Attachment G). These same results should be kept as a permanent record. Notwithstanding the need to record and report it is essential that confidentiality be maintained. Assistance with the compilation of epidemiological data may be derived from NH&MRC Supplementary Note 6: Epidemiological Research.

5.4 Specific records should be kept on semen quality. It is recommended that these records conform to the WHO guidelines for male infertility. These records should enable a retrospective analysis of the criteria necessary to accept infertile men for IVF and to advise patients of the likely success rates given their semen profile.

5.5 Centres should allow all donors and clients who provide information about themselves to the centre to have access to the record of that information and an opportunity to correct it.

6. *Ethics and Research*

6.1 IVF, whether therapeutic or experimental must only be practised within the guidelines published by the NHMRC. In addition, every IVF programme must have all aspects of the programme monitored by the Ethics Committee of the hospital or the institution concerned and conform to the regulations laid down by individual State legislation.

The roles of the Institutional Ethics Committee in monitoring the activities of those centres that practise IVF have been the subject of an NHMRC publication *Supplementary Note 4: In Vitro Fertilisation and Embryo Transfer.*

6.2 Every centre offering IVF and related reproductive technologies must have all research aspects of its programme approved by an institutional research committee before validation by the institutional ethics committee.

All centres practising IVF are encouraged to have an active research programme. The objectives of the programme should be to increase basic knowledge in the field of reproductive biology, to develop new and to improve existing procedures. The research programme should be based on sound scientific principles and be within the ethical guidelines for human and animal experimentation in accordance with the guidelines laid down by the NHMRC. Every endeavour should be made to publish results of research findings in authoritative peer reviewed journals. Any new procedure or technology developed as part of the research programme should only be adopted as normal clinical practice if it falls within ethical guidelines and is considered to be a suitable medical practice by RTAC.

An IVF centre without an active research programme can still receive accreditation provided it meets the other criteria laid down by the RTAC. Centres that do not have their own research programmes are encouraged to participate in epidemiological studies of IVF and participate in collaborative studies. These centres should also ensure that members of their staff receive the necessary training in new procedures developed in other laboratories before these are incorporated into the routine practice of their own centres.

6.3 The uses of gametes and embryos for research must comply with relevant state legislation and have the written consent of the donors. No embryo should be permitted to develop beyond the stage at which implantation would normally have occurred (Day 14).

6.4 Any experimentation involving fertilisation or embryos must be approved by the governing body or the associated institutional ethics committee and confined to ethical guidelines established by the NHMRC and the relevant State Government.

6.5 The institutional ethics committee must be satisfied that means exist for the couple to consent to the use of sperm, spare oocytes or embryos for research purposes and to indicate that excess embryos may be stored and when these should be disposed of.

6.6 The following activities are not approved:

6.6.1 keeping or using an embryo after the appearance of the primitive streak or after 14 days, whichever is the earlier;

6.6.2 placing an embryo in a non-human animal;

6.6.3 replacing a nucleus of a cell of an embryo with a nucleus taken from the cell of another person, another embryo or a subsequent development of an embryo;

6.7 Embryos which have been appropriated for a research project *must not* be used for any other purposes.

6.8 The science of all research projects involving the use of embryos should be supported by peer review undertaken by appropriate academic referees chosen by the institutional ethics committee.

7. *Quality Control*

7.1 All programmes will be subject to scientific and medical audit by RTAC.

7.2 Regular and appropriate internal review should be instituted to maintain laboratory and clinical standards.

7.3 Regular interdisciplinary meetings should be held to discuss IVF procedures and patient management and should be attended by the professional staff of the centre.

7.4 Staff of the centre should participate in in-service educational programmes and should be encouraged to attend national and international scientific meetings.

November, 1992

THE FERTILITY SOCIETY OF AUSTRALIA

REPRODUCTIVE TECHNOLOGY ACCREDITATION COMMITTEE

ATTACHMENTS TO THE CODE OF PRACTICE

A. Standards for Nursing Staff

B. Standards for Counselling Staff

C. Guidelines for Patient Information

D. Guidelines for Consent Forms

E. Screening for Donor Insemination and Oocyte Donation

F. Guidelines for the Storage and Use of Gametes and Embryos

G. National IVF Database

H. Hepatitis B and C Testing

I. Avoidance of Multiple Pregnancy

The guidelines to the Code of Practice include IVF, GIFT and all derivatives of these and other procedures to assist human reproduction in fertile persons.

ATTACHMENT A

STANDARDS FOR NURSING STAFF

From the commencement of IVF in Australia the principal link between patient and the close supervision of therapy has been the Nurse Co-ordinator. Being present in the Clinic all day, she is accessible to patients for both trivial questions and major problems. It is not surprising that most clinics depend on the Senior Nurse for much communication and structuring of treatment.

1. Nurses should have a tertiary degree in nursing or be a registered nurse or midwife.

2. They should have extensive in-service training in reproductive medicine, and should be given the opportunity of ongoing professional staff development.

3. They should have good communication skills and should be encouraged to undertake some training in counselling and the principles of psychology. In large cities it might be practicable to set up a part time training programme, possibly in conjunction with a faculty of nursing or health science.

4. Duties will include a range of nursing duties appropriate to reproductive technology and the provision of information and education to patients and other health professionals. In most clinics, record keeping would be a major responsibility.

November, 1992

ATTACHMENT B

STANDARDS FOR COUNSELLING STAFF

The following guidelines are offered to assist reproductive technology programmes and clinics in the establishment of appropriate counselling services for their patients. It is recommended that these guidelines be adopted as soon as practicable and that by 1995 all clinics will be able to claim they have reached the appropriate level of counselling service provision.

Some Australian states have reproductive technology legislation that specifically recommends the provision of counselling services.

It is recommended that counsellors meet the membership requirements of the Australian and New Zealand Infertility Counsellors' Association. These are:

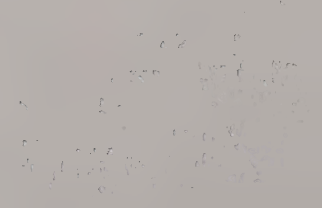
1. possession of a tertiary level academic qualification from a recognised institution. This qualification must include formal training in counselling

and

2. at least two years supervised counselling experience.

Further, it would be expected that all counsellors would engage in a programme of continuing professional education. They could also be expected to provide training programmes in basic skills to other staff of the clinic.

November, 1992



ATTACHMENT C

GUIDELINES FOR PATIENT INFORMATION

Contents of Plain Language Statement

The Committee believes that it is not possible to prepare a plain language statement that may be used uniformly. The Committee suggests, however, that every effort be made to ensure that the statement is written in language that is free from jargon and technical terms which patients may not comprehend. It is important to remember that some patients may be too nervous or reticent to ask about terms that they may not understand.

The Committee believes that the statement should at least address the following issues:

Details of the various professionals with whom the patient makes contact: clinic hours, contact times, after hours emergency phone numbers.

Eligibility criteria (e.g. state laws)

Guide to financial costs and rebates.

Explanation of the terminology: IVF, GIFT etc and a glossary of terms.

Reasons for particular procedures, in general: details of individual therapy would be given separately.

Risks associated with treatment:

Anaesthesia

Drug Therapy

Hyperstimulation

Complications of procedures

Uterine Bleeding

Infection

Cycle tracking methods:

- the need to collect blood/urine
- the use of ultrasound
- luteal phase observation and therapy
- pregnancy tests

Semen Collection

Egg Retrieval

Fertilisation

Embryo transfer

Cryopreservation

The number of embryos to be transferred

Options for excess oocytes and embryos

Outcomes: Success rate
Multiple pregnancy
Pregnancy losses
Congenital anomalies

The possibility of stress

Discussion on consent

Confidentiality

Information for out of town patients especially alternative night contact numbers

Reading lists

Provision of Information

1. Handing out an information sheet cannot be regarded as providing sufficient information, either for patient satisfaction or for informed consent.

2. It is essential that clear explanation of the treatment proposed or alternative treatment should be given, personally.

3. Although some information counselling may be given by the trained counsellor, the significant medical information must be given by the doctor and some can be given conveniently by the nurse co-ordinator. Each clinic must determine the best mix of professional staff to ensure that the appropriate information is given to each couple or individual.

4. External counsellors may be valuable for crisis counselling in other areas. They should prove especially helpful to work in conjunction with satellite clinics provided they have had some additional training at the parent clinic to apprise them of the special needs of the infertile patient and to educate them in the realities of IVF, i.e. what treatments are available, success rates, problems, complications etc.

5. Centres should make available a list of books or other publications which patients may wish to read.

November, 1992

ATTACHMENT D

GUIDELINES FOR CONSENT FORMS

The Committee suggests the following guidelines for the use and preparation of consent forms.

1. There should be a request by the patients for a procedure to be carried out.

2. Only one procedure is to be consented to on each form. Use a separate form (and a separate signature) for each extra option which may be consented to, for example: IVF, GIFT, PROST, donor oocytes, donor sperm, donor embryos, embryo freezing, oocyte freezing, oocyte donation to another woman, oocyte donation for research, semen donation to another couple, embryo donation to research, embryo donation to another couple.

3. The form is to be signed by both partners, witnessed and dated.

4. There should be an acknowledgement that there has been an exchange of information regarding the procedure between the patients and the medical practitioner, and that the patients have had adequate time and opportunity to ask questions about the procedure and its risks, and that all questions have been answered to the patients' satisfaction.

5. There should be an acknowledgement that the patients have been given detailed written information about the procedure.

6. There should be an acknowledgement of the risks and possible side effects or complications of the procedure.

7. There should be an acknowledgement that the procedure may be cancelled or unsuccessful.

8. There should be a clear statement as to whether the clinic views the procedure as a standard therapeutic procedure or as experimental, innovative therapy or a clinical trial. This is particularly important when new techniques are being introduced, for example, micromanipulation.

9. There should be an acknowledgement that the patients are free to withdraw their consent at any time.

10. In the case of cryopreservation of gametes or embryos, a record of the options consented to for their fate and the conditions of storage, including the wishes of the couple in the event of their death, separation or divorce. Following a major lapse of time, a further consultation should be offered to the couple in case there may be a change of their wishes.

1987
Review November, 1992

ATTACHMENT E

GUIDELINES FOR SCREENING FOR GAMETE DONATION

The Council of the Fertility Society of Australia considers the following as the minimum criteria for semen and oocyte donor programmes. These criteria are for screening and selection of donors.

1. *History*

1.1 Family history of inherited disorders.

1.2 Personal history of physical, mental or psychological disabilities.

1.3 Medical history of any children born to the donor.

1.4 All donors must sign a lifestyle declaration as required by the relevant State Department of Health or, if there is no such legal requirements, in terms similar to those set out below.

2. *Physical Examination*

Physical examination to exclude any obvious abnormality.

3. *Semen Analysis*

Detailed microscopic examination of semen for:

3.1 Potential fertility status
3.2 Signs of potential infection requiring further investigation.

4. *Oocyte Selection*

4.1 Clinical signs of potential infection requiring further investigation e.g. vaginal infection
4.2 Microscopic examination of oocytes in vitro (at time of collection)

5. *Serology*

The following serological tests to be performed:

5.1 Blood group and Rh (and any other blood group antibodies)

5.2 Syphilis serology - VDRL or similar

5.3 Hepatitis B and C surface antigen and anti-hepatitis core screen

5.4 HIV antibody titres

NB Repeat serology for syphilis, hepatitis B and C and HIV antibodies should be performed when donations are being repeated after an interval.

The Fertility Society of Australia, in the light of current information, considers that sero-conversion to HIV will occur within six months of infection. When gametes are frozen or are fertilised and the embryos are frozen, it is necessary to test donors six months after each donation to *clear* that donation of HIV infectivity. Opportunity should be taken to carry out repeat screens for syphilis and hepatitis B and C. Units may prefer to hold material for longer periods before re-testing.

6. *Other Tests*

For example:

6.1 Thalassaemia - where a donor has Mediterranean or Asian background, consideration should be given to screening for Thalassaemia trait by the measurement of the haemoglobin and mean corpuscular volume.

6.2 Tay-Sachs Disease - where a donor is Jewish, consideration should be give to screening for this autosomal recessive trait present in 1:50 Aschkena i Jews (in America) and 1:100,000 in the general population.

7. *Bacteriology*

7.1 Donated semen should be cultured periodically, including specific culture for gonococcus.

7.2 Cultures for communicable diseases, including chlamydia and herpes should be taken from the female genital tract of the donor prior to the time of oocyte collection, if indicated.

8. *Recording of Screening Information*

Good medical practice requires that the above screening information regarding the donor be retained.

9. *Physical Characteristics*

It is considered that the following information form part of the donor record.

9.1 height
9.2 build
9.3 eye colour
9.4 hair colour
9.5 skin colour
9.6 race

10. *Social History*

It is considered appropriate to record the following non-identifying donor information which may be of assistance to parents of children at a later date.

10.1 age
10.2 religion
10.3 nationality
10.4 race
10.5 country of birth
10.6 schooling
10.7 occupation
10.8 marital status
10.9 number of children
10.10 interests (hobbies, sports etc)
10.11 comment on donor personality by the donor
10.12 reason for assisting donor programme

11. *Confidentiality*

11.1 Care should be taken to avoid any disclosure of patient or donor identifying information, except with their written consent or in those cases where the donor is a volunteer known to the recipient.

11.2 Identifying information regarding donors should be retained as confidential records within the donor collecting unit in line with good medical practice.

11.3 Donors and recipients must be informed of relevant State legislation regarding transfer of identifying information.

11.4 Donors known to the recipient must not participate if State or Hospital regulations preclude this.

12. *Withholding Period*

Donated semen, after taking a sample for bacteriology screening, should be cryopreserved and quarantined for six months, when a repeat HIV test should be done on the donor. If negative, the semen may be used for insemination treatment. Fresh semen must not be used for donor insemination.

Donated oocytes after collection should be fertilised with the husband's semen (or a donor if appropriate) and the embryo deep frozen for six months when repeat HIV tests on the donor(s) must be made and have been reported negative before being used for donation. Embryo transfer may then be performed at a convenient cycle. It is strongly recommended that this should be the preferred method for oocyte donation.

13. *Fresh Oocyte Donation*

The use of fresh oocyte donation with embryo formation and embryo transfer should only be performed after full discussion of the respective risks of HIV transmission by the use of fresh or frozen/thawed embryos. The donor must have been checked for negative HIV status prior to the donation.

Many recipients may assume that in the case of donors ***known to them*** the element of risk of HIV infection is negligible. This cannot be presumed lightly and doctors facilitating oocyte donation should ensure personally that recipients understand the implications of the respective procedures before signing the consent form. The desirability of using frozen/thawed embryos in the first treatment cycle in all patients should be considered.

14. Mixing of oocytes from donors is prohibited and mixing of semen from donors is prohibited.

15. There must be no direct or covert coercion of a prospective donor and there must be no monetary or valuable consideration or other inducement for donation.

    Out of pocket expenses and any medical expenses incurred in respect of gamete donation may be reimbursed by the recipients.

16. In the case of women undergoing oocyte collection for their own treatment, it is considered unethical to hyperstimulate with the objective of deliberately obtaining an excessive number of oocytes/embryos so that some become available for donation.

17. The attached lifestyle declaration has been recommended in one State and is similar to that used by a blood transfusion service. A similar declaration should be used for semen and oocyte donation.

18. Copies of information sheets for patients, consent forms and lifestyle declarations must be submitted to RTAC for comment and approval. (Attachments: Suggestion for lifestyle declaration approved by RTAC 19th July, 1991)

19. Counselling of all donors and their spouses is strongly recommended.

October, 1991
Reviewed November, 1992

DONOR LIFESTYLE DECLARATION

AN IMPORTANT NOTICE TO ALL DONORS

There are some people in the community who ***must not*** donate sperm/ova because their lifestyle may give rise to conditions that would be detrimental to children born of their sperm/ova. If in doubt, please consult the staff at the clinic.

In the light of the present knowledge of AIDS (Acquired Immune Deficiency Syndrome) and although a screening test is currently performed on all gamete donations, this clinic must ask donors in the *at risk* groups not to donate sperm/ova. These people are:

- intravenous drug users (at any time in the past five years)
- prostitutes of either sex (and their clients)
- sexual partners of the above or of bisexual males

STATEMENT BY PERSON INTENDING TO DONATE SPERM/OVA

I, ...

(Name of Donor)

of, ...

(Address of Donor)

do hereby declare that, to the best of my knowledge:

1. I am not suffering from AIDS (Acquired Immune Deficiency Syndrome) or any disease related to it.

2. I am not suffering from night sweats, weight loss, persistent fever, diarrhoea or swollen glands.

3. (a) I have not engaged in male to male sexual activity during the last five years.

   (b) I have not engaged in anal intercourse and my spouse has not engaged in male to male sexual activity during the past five years.

4. I have not injected myself, or been injected with, any drug not prescribed for me by a registered medical or dental practitioner within the past five years.

5. I have not received a blood transfusion or recurring treatment with human blood products within the past five years.

6. Neither my spouse nor any sexual partner does come within the categories described in items 1, 2, 3, 4 and 5.

7. I have no communicable disease and I have never suffered from such an ailment in the past, except as follows:

.....

8. I am in good health and I have never suffered from any physical, mental or psychological impediment, disability or abnormality whether inherited or as a result of any disease, ailment or accident, except as follows:

.....

.....

9. I have read through the list of inheritable diseases and neither I nor any of my relatives have had any (except those indicated):

.....

Please Answer the Following:

1. Have you been treated with acupuncture, had your ears pierced or been tattooed within the past five years? Yes/No

2. Have you had jaundice or hepatitis in the past twelve months or been in close contact with any person suffering from those diseases within the past 6 months? Yes/No

I am signing this statement in the presence of a member of the staff of the clinic.

NAME: ..... *SIGNATURE OF DONOR:* .....
(Please Print)

SIGNATURE OF WITNESS: .....

If an individual is unable to give a clear declaration in response to all of the above statements before sperm/ova are donated, a medical officer must interview the donor.

I, ... have interviewed .....
(Name of Medical Officer)

and have found no reason why he/she should not donate sperm/ova.

SIGNATURE OF MEDICAL OFFICER: .....
DATE: .....

October, 1991
Reviewed November, 1992

ATTACHMENT F

GUIDELINES FOR THE STORAGE AND USE OF GAMETES AND EMBRYOS

1. Gametes should not be taken for the treatment of others from female donors over the age of 35 nor from male donors should over the age of 55 unless there are exceptional reasons for doing so. If there are exceptional reasons, these should be explained in the treatment records.

2. Gametes taken from women over 35 and men over 55 may be used for their own treatment, or the treatment of their partner. They should be offered clinical advice and counselling before deciding whether to proceed with treatment.

3. Gametes should not be taken for the treatment of others from anyone under the age of 18.

4. Sperm or eggs *must not* be taken from anyone who is not capable of giving a valid consent or who has not given a valid consent.

5. The possibility of donating gametes or embryos should not be raised during the potential donor's treatment cycle. If this is to be raised, it should be discussed before treatment is commenced so that the patient's views are not coloured by the situation during the course of treatment.

6. Information should be given to people consenting to the use or storage of embryos or to the donations or storage of gametes, on the following points:

   6.1 the procedures involved in collecting gametes, the degree of pain and discomfort and any risks to that person e.g. from the use of superovulatory drugs;

   6.2 the screening which will be carried out and the practical implications of having an HIV antibody test, even if it proves negative;

   6.3 the purposes for which their gametes might be used;

   6.4 whether or not they will be regarded under the State law as the parents of any child born as a result;

   6.5 whether or not State law permits donors to preserve their anonymity;

6.6 the information which centres collect and the extent to which that information may be disclosed to people born as a result of the donation;

6.7 that they are free to withdraw or vary the terms of their consent at any time, unless the gametes or embryos have already been used;

6.8 the possibility that a child born disabled as a result of a donor's failure to disclose defects, about which he or she knows or ought reasonably to have known, may be able to sue the donor for damages;

6.9 in the case of egg donation, that the woman will not incur any financial or other penalty if she withdraws her consent after preparation for egg recovery has begun;

6.10 that donated gametes and embryos created from them normally will not be used for treatment once the number of children believed to have been born from them has reached ten or the number of families created in which donated gametes from the same donor reaches ten, or any lower figure specified by the donor: when the panel of donors is drawn from an area of small population a lower limit than ten should be imposed;

6.11 that counselling is available.

7. Anyone consenting to the storage of their gametes, or of embryos produced from them *must*:

7.1 specify the maximum period of storage (if this is to be less than the maximum statutory storage period);

7.2 state what is to be done with the gametes or embryos if he or she dies, or becomes incapable of varying or revoking his or her consent.

8. Centres should ensure that people do not feel under any pressure to give their consent, particularly when the donor is known to the recipient.

9. If the donated gametes are to be used for treatment and the donor is married or has a long-term partner, centres should ask their partner to consent in writing to the use of the gametes for treatment.

10. In the case of oocyte donation, the centre should be prepared to accept the financial loss if the woman withdraws after preparation for egg recovery has begun.

11. ***Non-Use of Eggs or Sperm***

11.1 Eggs or sperm which have been subjected to procedures which carry an actual or reasonable theoretical risk of harm to their development potential and embryos created from them, should not be used for treatment. Treatment centres should ensure that sufficient scientific evidence is available to establish that any procedures used do not prejudice the development potential of the gametes or embryos.

11.2 Similarly, embryos which have themselves been subject to procedures which carry an actual or reasonable theoretical risk of harm to their developmental potential should not be used for treatment. Treatment centres should ensure that sufficient scientific evidence is available to establish that any procedures used do not prejudice the developmental potential of the embryos.

11.3 Gametes or embryos which have been exposed to a material risk of contamination which might cause harm to recipients or to any resulting children should not be used for treatment. If there is any doubt, centres should seek expert advice.

11.4 Women should not be treated with the gametes or with embryos derived from the gametes of more than one man or woman during any treatment cycle.

12. ***Termination and Disposal***

12.1 Where an embryo is no longer to be kept for treatment, the centre should decide how it is to be allowed to perish and what is to happen to the perished material. The procedure should be sensitively devised and described and should be communicated to the people for whom the embryo was being stored if they so wish.

12.2 In the case of embryos used for research, the centre should decide at the outset the duration of the culture period, the method which is to be used to terminate development and the procedure which will ensure that embryos do not continue to develop after fourteen days or (if earlier) the appearance of the primitive streak.

Acknowledgement: A number of the above guidelines have been derived from the *Human Fertilisation and Embryology Authority: Code of Practice: London.*

November, 1992

ATTACHMENT G

INFORMATION TO BE PROVIDED ANNUALLY TO THE NATIONAL PERINATAL STATISTICS, UNIT/FERTILITY SOCIETY OF AUSTRALIA

NATIONAL DATABASE ON IVF & RELATED TECHNIQUES

It is mandatory that centres should supply the data requested for the compilation of statistics by the AIH National Perinatal Statistics Unit and the Fertility Society of Australia. This material may vary from time to time, depending on the introduction or modification of treatment regimens. The material is supplied confidentially to the AIH-NPSU to indicate the current Australian and New Zealand results of treatment.

November, 1992

ATTACHMENT H

HEPATITIS B AND C TESTING IN IVF AND RELATED PROCEDURES

It is recommended by RTAC that all couples undergoing IVF and related procedures should be tested for Hepatitis B and C. The reasons for this recommendation are as follows:

1. ***Neonatal Infection*** Vertical transmission of Hepatitis B and C to a neonate can be prevented by active and passive immunisation if it has been established that the mother is a carrier. Pre-pregnancy testing as a part of infertility investigations is a logical way to make this diagnosis. The National Health and Medical Research Council and the Royal Australian College of Obstetricians and Gynaecologists both recommend that all women should be tested for Hepatitis B and C during pregnancy. It is important that when this is done that the result of the test be made known to the patients.

2. ***Protection of Staff*** Medical, nursing and laboratory staff may be exposed to large numbers of blood and semen samples during these procedures. Not all IVF Unit staff are immunised against Hepatitis B and C, even though they are aware of the increased risk in this particular situation. Hospital staff, in addition to the staff of the IVF unit, are frequently involved in the care of these patients. Universal procedures noted in 4.1 of the Code of Practice should be adopted for all personnel.

3. ***Contamination of Laboratories*** There is a small but identifiable risk that laboratory glassware and equipment may become contaminated following treatment of patients who are unrecognised Hepatitis B and C carriers.

4. ***Medico-Legal Aspects*** Where donor gametes or embryos are used the serological status of the recipients (as well as the donors) must be established prior to treatment.

October, 1989 (Hepatitis C included November, 1992)

ATTACHMENT I

AVOIDANCE OF HIGH MULTIPLE PREGNANCY

In view of the number of articles criticising the incidence of high multiple pregnancies arising from IVF and related procedures and the consequential resulting perinatal morbidity and mortality, RTAC requests that all clinics consider very carefully the need before transferring more than two embryos or oocytes in each treatment cycle. The guideline that up to three and, in exceptional circumstances, four embryos or oocytes may be transferred in any one cycle must not be exceeded. The phrase in *exceptional circumstances* must not be interpreted liberally. In future, RTAC will request additional information from clinics reporting numbers of high multiple pregnancies. For example, age 40 and over is not regarded as a criterion for the transfer of 4 embryo/oocytes in the first treatment cycle as *exceptional circumstances*.

October, 1991
Review November, 1992

MANATU MAORI
MINISTRY OF MAORI AFFAIRS

GUIDELINES FOR THE USE OF ASSISTED REPRODUCTIVE TECHNOLOGY

SUBMITTED TO THE INTERDEPARTMENTAL MONITORING COMMITTEE ON ART BY ...

STATEMENT OF INTENT

1.0 This working group recognises that there is a multiplicity of social, cultural, ethical, medical and political views surrounding Assisted Reproductive Technology (ART). More specifically this particular field of medical intervention in concert with its associated research, indicates that there are numerous implications for the future. ART has implications for valuing human life and the sustenance of past, present and future family relationships. Therefore it is from the perspective of valuing human life and protecting family relationships that this working group choose to approach ART and the implications for Maori.

1.1 The substantive social and cultural dimensions of ART highlight the need for whanau, hapu and iwi to debate the issues more fully. It was agreed by the working group that the action to be taken at this time would be to identify components for developing guidelines that can be applied within a New Zealand context, and specifically offer protection and culturally safe options for Maori. In addition, the workings submitted below are framed within a broad social and cultural context and it is acknowledged that more extensive work will be required to further develop as well as, include both the technical and clinical dimensions of ART.

1.2 Also, this group is mindful that in 1987 the Fertility Society of Australia established the Reproductive Technology Accreditation Committee (RTAC). It is our understanding that this committee has devised a set of accreditation guidelines and in line with these a number of fertility clinics in this country have received accreditation. While this is acknowledged as a positive move, it is important to note that the RTAC guidelines are void of any explicit cultural perceptions. Therefore it is the wish of this working group that the guidelines submitted below be included in formulating a set of precepts that recognise tangata whenua. We recommend that the RTAC guidelines be adapted to include those submitted by this working group.

1.3 In moulding the guidelines outlined below, we have constantly kept in mind:

- the values and tikanga inherent within whanau, hapu and iwi;
- the need for a process that is culturally supportive and safe;
- the need to protect whakapapa;
- the need to protect fertility, and;
- the need to protect individual and informed choice.

THE TREATY OF WAITANGI

2.0 The Treaty of Waitangi encapsulates and reaffirms the pre-existence of the values and norms inherent within Maori society. Also the Treaty re-states that two sovereign peoples have entered into an agreement as equal partners, and that this relationship and the manner in which it might be enhanced and sustained has significant implications at several levels. These are, the drARTing, implementing and monitoring of policy. Integral to this process is participation and representation. Included also is the allocation of resources, the provision and types of services available and cultural perspectives in all policies. It is the view of this working group that the embodiment of the Treaty of Waitangi at all levels and in all processes associated with ART ensures that the role and status of Maori in the development of New Zealand society is advanced and recognised.

2.1 The Treaty also embodies a number of fundamental principles that are conducive to giving effect to the issues raised above. In addressing these, this working group makes the following statements:

- That the Treaty of Waitangi is the founding document of New Zealand society, from which Maori rightfully give expression to their authority, responsibilities, values and expectations;
- That as a Treaty partner the Crown has a responsibility to ensure that all health technologies protect the integrity of whanau, hapu and iwi;
- That whanau, hapu and iwi have a right and responsibility to care and nurture their own;
- That partnership and co-operation is imperative to ensure the effective and efficient use of resources, skills and knowledge;

- That all recipients and donors of ART have the right to direct the use of ART in a manner that is supportive of their cultural values and norms;

- That all children conceived, and born as a result of ART have an inalienable right to full knowledge of their culture and identity;

- That all people who choose to use ART are enabled to make informed decisions and give informed consent based on their cultural values and norms; and

- That the Crown has a responsibility to ensure that effect is given to various cultural options in respect to infertility and that these are resourced.

SPECIFIC AREAS OF CONCERN

3.0 This working group is particularly concerned with issues that relate to the protection of whakapapa and informed choice and consent, as well as ensuring that across all technologies the processes involved are culturally supportive and safe. In addition, it is the view of this working group that there is a need to promote the prevention of infertility within the context of todays health risks.

NEED FOR A PROCESS WHICH IS CULTURALLY SAFE

4.0 The need for fertility clinics to devise and implement culturally supportive and safe processes in respect of ART arises from the recognition that this technology is being sought by Maori recipients and donors. Culturally safe processes recognise that the culture of the clients may vary, from the culture of the institution. Therefore such a process should reinforce cultural identity, fosters trust and is mutually educative and supportive. This process umbrellas focal areas of this paper such as, counselling, protection of whakapapa, informed choice, prevention of infertility and protection of individual rights.

COUNSELLING

5.0 Because of the very nature of the processes associated with ART, it is inescapable that strict clinical conditions exist. Science and technology are an enigma to most people. Because of this an element of control is taken away from the patient and put in anothers hands. Staff therefore must be both professional and sensitive when dealing with people who are entering an unfamiliar environment. Also, there is a need for privacy in all aspects of the treatment, for being kept informed during the process

and the need for comfort. Needs will vary at different stages during the process.

5.1 We believe that counselling, along with the principle of informed consent and decision making, are fundamental to the development and implementation of a culturally supportive and safe process in respect of all ART treatment, research and the storage of embryos and gametes. That counselling must be provided in an environment that caters for the needs of Maori donors, recipients and their whanau.

5.2 In order for whanau to be supportive they must understand the scientific process as well as the emotional stress which a patient or couple are going through. Counselling staff must be able to provide information, as well as, enable the recipients, donors and whanau to fully understand the implications of the treatment and the emotional and spiritual dilemmas that will be experienced.

5.3 Maori who seek ART must have access to expert counselling before consent to treatment is given. This counselling must consider the cultural implications of such procedures the use and storage of embryos, or the donation and storage of gametes.

5.4 This working group has taken the following from of "*Code of Practice for the Human Fertilisation and Embryology Authority*" in Britain as a guide to the types of counselling that should be made available to recipients, donors and whanau. It should be noted that cultural counselling has been inserted by this working group.

(i) Implications counselling : this aims to enable the person/couple concerned to understand the implications of the proposed course of action for herself or himself, for their respective families and for any children that may be born as a result of ART;

(ii) Support counselling : this aims to give emotional support at times of particular stress;

(iii) Therapeutic counselling : this aims to help people understand and cope with the consequences of infertility and treatment, and to help them to resolve the problems which these may cause; and

(iv) Cultural counselling : this aims to enable Maori to understand the implications of ART for whakapapa and to explore other cultural options as viable treatments for infertility. Provisions should also be made for whanau counselling when required.

5.5 Counselling should ideally begin after initial contact has been made with service providers of ART and should continue throughout treatment, After birth and at various life stages of the child as identified by either the recipients and donor, or their families. Also counselling must be viewed

as a safety mechanism to minimise the risk of exploiting those who may be particularly vulnerable at the time of seeking treatment or at any other stage of the treatment.

5.6 To ensure that all the components of counselling are implemented in a manner that advances a culturally supportive and safe process it is envisaged by this working group that Maori Counsellors who are trained in all of the above be appointed to all ART clinics and treatment centres. This working group recommends that clinics facilitate any initial and all on-going training in respect to the four distinct areas of counselling.

PROTECTION OF WHAKAPAPA

6.0 ART often involves the use of donor gametes and as a result there is a party involved who will not be participating in the up bringing of the child. Therefore it is likely that the child will grow up not knowing anything about the donor biological parent. Furthermore, the Status of Children Amendment Act 1987 states that the couple who sought treatment are the parents of the child born as a result of ART. This legislation conflicts with Maori values and norms, specifically in respect to whakapapa.

6.1 Whakapapa is the mechanism by which individual whanau members establish ascent to an eponymous ancestor. This element establishes and determines an individuals status, and formalises their relationships with others who are also able to trace their ascent to a common ancestor. A vital step in this process is having full knowledge and access to information and people who have the same biological connections. Whakapapa also re-affirms and consolidates the inter-relationships that Maori have with the tangible and intangible dimensions of the environment. As such it is the process used by whanau or individual whanau members to establish their status as "*people of the land*". Whakapapa can be viewed as the sum total of an individuals cultural basket in which is contained the essential ingredients for identity, self awareness and self preservation. While the focus is often on the identity of the child born as a result of ART, this working group stresses the importance of this information for the cultural identity of future generations.

6.2 Explicit in whakapapa is the real and undisputed knowledge that children have two biological parents and that the child is the offspring of whanau, hapu and iwi. In view of this, all of these social groupings have an interest in that child. However, the very nature of ART together with the Status of Children Amendment Act 1987, undermine an individuals birth right and claim to their whakapapa and thus their right to full access to their cultural heritage.

6.3 This working group is adamant that there is a need to protect whakapapa out of which will fall the protection and preservation of past, present and future family relationships. Protection of whakapapa will require that all children born as a result of ART have unconstrained access to information that readily identifies the child's biological parents. We are aware that this raises issues of access to information, the wish for anonymity of the donor, as well as the rights of children and parents. However, it is issues such as these that need to be worked through in a systematic and negotiated manner with Maori. Until these issues are worked through, they are matters which should be covered during counselling, specifically for Maori recipients, donors, and their whanau.

THE NEED FOR INFORMED CHOICE

7.0 In order to make informed choice full information must be given to those seeking treatment. This includes:

(i) Whether all other cultural options have been considered;

(ii) Whether information is available about the donor. Whether the donor is willing to share aspects of his/her identity and the parameters of this. Whether the couple has considered a donor from their own whanau, hapu, or iwi.

(iii) Whether the couple have considered the financial implications of the treatment.

7.1 We would recommend that the guidelines as set out in "*Part 4 Information, from the Code of Practice for the Human Fertilisation and Embryology Authority*" from Britain, be the guidelines which are adopted in New Zealand.

7.2 In regard to the storage of gametes and embryos, anyone consenting to the storage must specify the maximum period of storage and state what is to be done with the gametes or embryos if he or she dies or become incapable of varying or revoking his or her consent.

NEED TO PROMOTE THE PREVENTION OF INFERTILITY

8.0 Appropriate fertility management education and service delivery is the key to the prevention of infertility in many instances.

8.1 In view of this, this working group sees fertility management education as a vital component in the prevention of STD's and infertility. Eliminating the preventable causes of infertility should be a high priority for IMCART.

NEED TO PROTECT THE INDIVIDUAL

9.0 The Status of Children Amendment Act 1987 places the legal rights in regard to the child with the parents who have sought the treatment. The donor of the gamete is absolved of all liabilities in regard to the child. The very pragmatic viewpoint of this legislation does not address an individuals social, cultural or emotional needs. There are rights of many individuals involved in assisted reproductive technology treatment.

9.1 Protecting donors from being identified, while protecting their rights, will restrict the rights of children to knowledge of their biological and cultural origins. Another issue is the right of the legal parents whether or not to tell the child of his or her origins. All of these issues must be viewed within the context of protecting whakapapa which bestows upon the child rights to have access to and full knowledge of ancestry.

9.2 While this working group acknowledges the individual rights of consenting recipients and donors in the treatment of ART, this group is of the view that these rights should not in any way overshadow or impede the rights of any children born from ART to be fully informed of their cultural identity.

CONCLUSION

10.0 In conclusion it must again be stated that ART has many foreseen and unforeseen consequences and implications for valuing human life and the preservation of past, present and future family relationships. In respect to Maori recipients and donors the need to protect whakapapa within the context of todays health risks and technological practices must remain at the fore-front of any policy developments, accreditation processes and legislation. Furthermore, in the national interest and as Treaty partners, government has a responsibility to ensure that those who administer all the dimensions of ART, inclusive of such things as research and the storage of gametes and embryos are not absolved from their Treaty responsibilities. At this point in time this requires that government continues to monitor developments in the field of ART to ensure that culturally safe processes are developed and implemented through the establishment of indigenous ART precepts.

Working Party for ART
Manatu Maori

APPENDIX F

SUBMISSION OF THE HUMAN RIGHTS COMMISSION TO THE MINISTERIAL COMMITTEE ON ASSISTED REPRODUCTIVE TECHNOLOGIES

INTRODUCTION

JURISDICTION OF HUMAN RIGHTS COMMISSION

The long title to the Human Rights Act 1993 states that it is an act:

> "*...to provide better protection of human rights in New Zealand in general accordance with the United Nations International Covenants on Human Rights*"

Section 5 of the Human Rights Act 1993 gives the Commission various functions and powers, including the functions:

(i) To make public statements in relation to any matter affecting human rights, including statements promoting an understanding of, and compliance with, the Act ;

(ii) To enquire generally into any matter, including any enactment or law, or any practice, or any procedure, whether governmental or non-governmental, if it appears to the Commission that human rights are, or may be, infringed thereby.

(iii) To prepare and publish, as the Commission considers appropriate, guidelines for the avoidance of acts or practises that may be inconsistent with, or contrary to, the provisions of the Act.

The Commission considers section 5 confers on it a responsibility to encourage compliance with international human rights instruments and recommend courses of action on any matters affecting human rights. Some human rights issues arise with respect to aspects of assisted reproductive technologies (ART) and part of the Commission's submission is based on this human rights perspective.

The international human rights perspective requires reference particularly to those international instruments ratified, and therefore binding on New Zealand, which concern various issues which are raised by the ART debate. Of primary consideration is the Convention on the Rights of the Child, ratified by New Zealand in 1993, Article 8 of which states,

> "*States Parties undertake to respect the right of the child to preserve his or her identity, including nationality, name and family relations as recognized by law without unlawful interference.*"

The instruments also include the Universal Declaration of Human Rights which recognises the right to found a family, the right to adequate health care and the right to share in scientific advancement and its benefits (articles 16, 25 and 27) and the International Covenant on Civil and Political Rights.

The Commission invited representations on the issue of access to ART from members of the public through public advertising and through directly contacting a large number of persons and bodies representing those groups currently or potentially discriminated against in respect of access to ART. A list of the persons and bodies that submitted their views to the Commission is annexed to this submission (with the exception of a single woman seeking access to ART who wished to remain anonymous).

When examining the issue of access to ART from a rights perspective, it becomes apparent that interested parties may have conflicting rights and that consideration must be given to a balancing or prioritising of these rights. The rights most obviously in potential conflict are the rights of the prospective parent or parents and the rights of the child. Some New Zealand legislation has given paramountcy to the rights and welfare of children, for example, the Guardianship Act 1968. Some has provided only that the welfare of the child should be taken into consideration along with other factors eg. the Children, Young Persons and their Families Act 1989.

The Commission notes that section 13(5) of the United Kingdom's Human Fertilisation and Embryology Act 1990 provides that:

> *"A woman shall not be provided with treatment services unless account has been taken of the welfare of any child who may be born as a result of the treatment (including the need of that child for a father), and of any other child who may be affected by the birth."*

The U.K. has legislated for a consideration of the child's welfare but has not made it paramount. The Commission believes that consideration of children's rights issues is essential in this area. There is, however, a concern that these issues can be subject to prejudice regarding single or homosexual parents or less conventional family circumstances or environments.

The Commission also has an interest in ART in relation to the anti-discrimination clauses of the Human Rights Act. The Commission considers that fertility treatment services fall clearly within the meaning of goods, facilities or services referred to in section 44 of the Act. Section 44 provides that:

> *"(1) It shall be unlawful for any person who supplies goods, facilities, or services to the public or any section of the public -*
>
> *(a) To refuse or fail on demand to provide any other person with those goods,*

facilities, or services ; or

(b) To treat any other person less favourably in connection with the provision of those goods, facilities or services than would otherwise be the case, -

by reason of any of the prohibited grounds of discrimination."

Many of the current practices of ART providers are prima facie in breach of section 44. This is a matter of concern to the Commission and to the ART providers and their clients. The Commission may receive a complaint of discrimination which could result in action being taken against fertility clinics at the Complaints Review Tribunal and possibly the High Court.

The issue of compliance with the law, and in particular the Human Rights Act, will be of great importance to the Ministerial Committee. Guidelines that comply with scientific, medical and ethical standards yet breach the law will be of little use as providers will potentially have to choose between complying with such guidelines or with the law. Such a conflict would be unacceptable and should obviously be avoided.

To avoid this conflict, guidelines which are potentially in breach of the Human Rights Act will need to be provided for in legislation. Section 151 of the Act provides that, the Human Rights Act is subordinate to other legislation and will not take precedence over any conflicting legislation. Guidelines supported by a statute will therefore be upheld even if in conflict with the anti-discrimination provisions of the Human Rights Act. In stating this, the Commission is not suggesting that discrimination in the provision of ART be enshrined in legislation, it is merely pointing out the legal pitfalls in the formulation of guidelines. A related legal problem is the effect of section 152 of the Human Rights Act which provides that section 151 will expire on 31 December 1999. New Zealand's legislation will thereafter be affected by the provisions of the Human Rights Act. Under the present legislative scheme, discriminatory practices protected by specific legislation will therefore need to be revised in any event by 31 December 1999 .

The following discussion examines the grounds of discrimination in the provision of goods and services that are prohibited by section 44. It becomes apparent when examining these grounds that what is essentially at issue is the provision of or access to ART for minority groups as those groups most requiring protection from unlawful discrimination are minorities or perceived minorities. The grounds upon which discrimination is unlawful under section 44 are listed in another section of the Act, section 21.

UNLAWFUL DISCRIMINATION AND ACCESS TO ART

Section 21 states that the prohibited grounds of discrimination are sex, marital

status, religious belief, ethical belief, colour, race, ethnic or national origins, disability, age, political opinion, employment status, family status or sexual orientation. While some of these categories bear little or no relation to the question of who may receive fertility treatment or services, others have been fundamental, both in New Zealand and elsewhere, in determining to whom ART is available. The following commentary examines each of the prohibited grounds as they pertain to access issues. Possible options are suggested where appropriate.

SEX Currently access to ART has been unaffected by issues of discrimination that fall within this category. It is possible, were surrogacy to be permitted and practised, that single men would seek to commission children to be carried and borne by surrogate mothers. As the law stands now, denial of such a service by providers would be unlawful. However, in such situations where ethical considerations, competing interests and rights are in conflict, provision might be made for individual assessment of novel cases.

MARITAL STATUS It appears that ART providers in New Zealand only offer treatment to heterosexual couples in stable relationships. Providers claim their cautious approach to this question, particularly as it affects single women, is due to the lack of legal precedents and ethical guidelines as well as a fear of drawing negative attention to the services themselves. However, denying fertility treatment and services to people because they are not living in a relationship in the nature of a marriage is in breach of the Human Rights Act. There seems little justification for discriminating on these grounds when in both legislation and court decisions broader conceptions of what constitutes a family and the optimum environment for raising children are now being employed. The shift in current legislative and judicial thinking reflects the reality that family composition in New Zealand society is becoming more diverse and single parenthood is becoming increasingly common.

RELIGIOUS BELIEF, ETHICAL BELIEF AND POLITICAL OPINION While it seems unlikely that provision of access to ART will be affected by these grounds, discrimination on any of them would be unwarranted. At present, however, donors may specify the religion of the recipients they are willing to donate to. The issue of donor discrimination is discussed more fully below.

COLOUR, RACE, ETHNIC or NATIONAL ORIGINS It would appear that providers are currently discriminating against prospective clients in a number of ways in the areas of colour, race, ethnicity or national origins. Given that providers attempt to match donors' characteristics with those of recipients', prospective clients may be indirectly discriminated against by virtue of a scarcity of gamete donors from particular racial, ethnic or national groups.

Anecdotal evidence suggests that providers have less philosophical difficulty in providing recipients of European origins with gametes from other racial or ethnic groups than the reverse. This is difficult to justify, particularly as lack of donor gametes from non-European racial and ethnic groups is cited as a reason why

recipients drawn from such groups may wish to use European gametes as a last resort. Providers could alleviate this deficiency by recruiting donors from a wider range of ethnic communities. This may be accompanied by promoting education and information about ART amongst these communities in a culturally appropriate manner.

Prima facie, providers who deny recipients fertility treatment because of a lack of matched racial or ethnic genetic material would be in breach of the Human Rights Act. In determining whether miscegenation by ART is an infringement of individual rights to cultural determination and preservation of national identity, we need to ascertain how ART children will experience the ethnic, racial or national aspects of their genetic origins. The role donors play in the lives of their ART offspring, the extent to which such children exhibit marked physical differences from their recipient parents, and the value attributed to specific racial, ethnic and national cultures during the children's upbringing will affect consideration of this issue.

The Commission has sought consultation with Maori groups on the implications of ART on the protection of whakapapa.

A number of concerns particular to Maori have been raised. They include the following:

- ART will interfere with whakapapa, land rights, tikanga, wairua, whanau, ancestry.
- ART will raise problems regarding eligibility to enrol on the Maori electoral role.

One submission received by the Commission referred to *whangai* which means that a woman who cannot have a child is usually given a child at birth by one of her whanau which she can rear as her own. It was submitted that this traditional way of dealing with infertility was more appropriate than the pakeha solutions of adoption and ART.

The major concern for Maori is related to the emphasis Maori place on genealogical identity. Identity has a greater and different importance for Maori than Pakeha.

> *'The Maori will always want to know "who are you and where do you come from". '*

This concern with identity will be of significance from the children's welfare perspective. The fact that the effects on Maori children of being the product of ART are likely to be more significant than the effects on pakeha children will be a matter the Ministerial enquiry will need to address. Guidelines regarding donor identification which are appropriate to pakeha may not necessarily be appropriate to Maori.

The Commission is continuing to seek consultation with Maori and will inform the

Ministerial Committee of the results of these consultations when they are available.

DISABILITY The definition of disability under the Human Rights Act is broad. It includes physical disability or impairment, physical illness, psychiatric illness, intellectual or psychological disability or impairment, any other loss or abnormality of psychological, physiological or anatomical structure or function, reliance on a guide dog, wheelchair, or other remedial means or the presence in the body of organisms capable of causing illness.

As with the other prohibited grounds of discrimination, refusing or failing to provide services to those people who fall within the definition of disability or to treat them less favourably in the provision of services is unlawful. The exemptions in relation to disability are stated in section 52 of the Act. Exceptions include refusing to provide facilities or services to people whose disability would require that such provision be made in a special manner which could not be reasonably expected of the provider; or providing services on terms which are more onerous than for other people, if the person's disability requires the provision be provided in a special manner which the provider cannot be reasonably expected to provide without the imposition of more onerous terms.

The current approach taken by providers to disabled recipients is cautious and is, as the law stands, in breach of the Human Rights Act. Decisions to provide ART to disabled people appear to be guided by a concern for the best interests of the child and, in general, the caution exercised in this area is understandable in terms of the complex social and ethical implications. Implicit in such a restricted approach, however, are assumptions that disabled people will not make good parents or that they will be the children's sole or principal care givers. This makes no allowance for the possibility that, as one submission to the Commission noted, parents with disabilities may have a wide support network who will be prepared to play a significant role in the children's upbringing. Procedures for assessing the prospective parent's ability to parent and the children's best interests are recommended in order to prevent unjustifiable discrimination of potential ART recipients.

As in all contentious cases involving discrimination and ART, the question of whether disabled people should have access to these technologies must depend on the balancing of various factors which affect those people's capacity to parent children. It has been submitted to the Commission that if fertile people are not subject to controls on their reproductive rights, neither should the infertile. However, ART presents a situation where more resources, people and thought go into producing a child than are usually involved in pregnancy resulting from sexual intercourse, and the setting in place of some measures which may safeguard the children's rights to adequate care and protection is one advantage ART may have over nature. If the extent and nature of the prospective parent's or parents' disability would clearly place any child born as a result of fertility treatment at real risk or would severely disadvantage the child's well being then refusal of treatment would be defensible.

Those people who are infertile due to a physiological inability to conceive or bear children, (and this would include those women whose health would be severely at risk by carrying a pregnancy to full term) appear to fall squarely within the definition of disability under the Act. Those who are what may be termed 'socially infertile', namely those who do not wish to have or have no opportunity to have sexual relations with the opposite sex, would be included under other grounds such as sexual orientation or marital status.

AGE Discrimination based on the age of recipients is in breach of the Human Rights Act. When the recipients' age presents no substantial conflict with the rights of the potential child, access should not be refused. At present it appears that men do not experience discrimination by private providers on this ground, and given that the medical technology exists to make post-menopausal pregnancy relatively safe for mother and child, older women should not be discriminated against.

EMPLOYMENT STATUS The high costs of fertility treatment make access for low-income earners and beneficiaries difficult. These procedures are expensive to both providers and consumers, even in the single public hospital which provides fertility treatment. It is suggested that more provision of ART could be made available through the publicly funded health system to offset the indirect discriminatory effect of costly private fertility services.

FAMILY STATUS The definition of family status includes having responsibility for the full- or part-time care of children or dependants, having no responsibility for care of children or dependants, being married or in a relationship in the nature of a marriage with a particular person, and being a relative of a particular person. Any discrimination in the provision of fertility services on these grounds would be unwarranted. However a controversial issue which could fall within this area may be prospective recipients being refused treatment because of a consanguine relative having a disability which the provider considers genetically risky. Perhaps this is an area where recipients should be permitted to make their own informed choices.

Another issue may be the use of donated genetic material from family members in a way which if it had occurred through sexual intercourse would constitute incest, for example a woman being inseminated with the semen of her step-son.

SEXUAL ORIENTATION Any discrimination on this ground, which means having a heterosexual, homosexual, lesbian or bisexual orientation, is unlawful. It should be recognised that homosexual parenting is not a novel issue but a social reality, and that many children are already being raised by homosexual parents. Although statistics are unavailable for New Zealand, one figure given in the 1990 *Harvard Law Review* was that between 6 to 14 million American children are currently being reared by gay men and lesbians. A large number of homosexuals have had children in heterosexual relationships before 'coming out'. One study estimates that 3 to 5 million American homosexuals have parented children within heterosexual

relationships[1]. Others have elected to have children while in same sex relationships[2]. These children are often the result of private donor insemination arrangements which would remain covert if access to ART is denied.

DONOR ISSUES

Donors are routinely screened by providers. The different providers have similar but varying criteria that they apply in order to determine whether an individual is accepted as a donor of sperm or oocytes. Some providers require donors to be married and to have children. Providers generally screen for chromosomal defects, congenital disabilities and impairments which may effect the resulting child and HIV.

Providers are not inhibited by the provisions of sections 21 and 44 of the Human Rights Act in their screening and selection of donors. The reason for this is that donors are not receiving goods, services or facilities that are provided to the public. Instead, they are technically making a gift. Gifting is not covered by the Human Rights Act and providers are therefore free to select donors as they see fit.

Concerns have been expressed to the Commission that the donor selection process may entrench disability-phobic attitudes, promote eugenic thinking and employ discriminatory value judgements in determining the undesirability of certain gene pools. The Commission considers that guidelines for donor selection would be more appropriately determined by ethical and medical experts (with lay representation). With regards to the race of donors, we refer to the discussion above concerning the access problems for certain racial groups caused by the unavailability of same race donors. The Commission suggests that active steps be taken to promote donation for ART among communities deficient in donors.

An interesting issue is raised by the conditions that donors may make regarding the recipients of their sperm or oocytes. These conditions may be prima facie in breach of the Human Rights Act. For example, a donor may wish to specify that his sperm is not provided to a single person or a lesbian. The donor who is making a gift is not bound by the anti-discrimination provisions of the Act. The providers, however , who are offering a service to the public are so bound. To what extent can a provider carry out a donor's wishes without incurring liability under the Human Rights Act?

The Commission considers that providers will not be liable under the Human Rights Act for enforcing donor conditions if those conditions are binding on the provider and are not merely discretionary guidelines. Donor prejudice should however be

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[1] Hartinger, Brent "A case for Gay Marriage" in *Commonweal* 22 November 1991, at p 682.

[2] The study above states that, at least 1000 children have been born to homosexual parents in the San Francisco area in the 5 years prior to 1991. (Hartinger, 1991, 682).

addressed through education. It would give rise to an anomaly if ART families became increasingly less representative of society as a result of donor prejudice.

There is a variation of practice in New Zealand and Australia concerning the identification of donors. Some providers will only select donors who are willing to be identified in the future to their genetic offspring. Other providers do not make this requirement of donors. The types of information sought from donors and the availability of this information vary from provider to provider and require standardisation. This is an area where childrens' rights should weigh heavily. It has been suggested that a centralised register of donor information should be maintained for access by recipients of ART and their resultant offspring. The Commission supports this suggestion provided that stringent privacy controls are set up to protect all parties. Willingness to be identified to recipients and the children should perhaps be a mandatory requirement for donors.

As the analogous New Zealand experience of adoption has shown, anonymity of donors would most likely lead to negative personal repercussions for their genetic progeny. It is commendable that generally New Zealand providers ensure donor information is available to recipients and offspring of fertility treatment. Ideally, some minimum level of contact between donors, recipients and, possibly, the children could be provided. Information regarding donors should be collected by providers in a manner and form complying with the information privacy principles in the Privacy Act 1993. This information would preferably include details of the donor's physical appearance, racial, ethnic or national origins and cultural affiliations. Such information should be centrally stored and disclosure closely regulated.

MEDICAL INSURANCE

The Commission has canvassed the major medical health insurers as to whether they provide cover for infertility treatment. None of them do so, infertility falling into the principal exclusions of the policies along with treatment for cosmetic purposes,dental treatment, AIDS, HIV and various other chronic conditions.

If it is accepted that infertility is a disability then it would seem that infertile people are being discriminated against as a group by medical insurers. Section 48 of the Act allows insurers to treat persons or groups of persons differently if the different treatment is based on actuarial or statistical data. The Commission intends to request the medical insurers to provide it with the data that is being relied upon to justify the exclusion of infertility treatment pursuant to section 48 (2) (a). Pursuant to s 48(2) (b) the Commission may then request the views of the Government Actuary on the justification for the reliance and the different treatment.

It has been submitted to the Commission that a significant percentage of infertility is the result of sexually transmitted diseases (STDs). It would seem logical that if

treatment of STDs are covered by medical insurance (as they are with the exception of AIDS and HIV) the consequences of STDs should also be covered.

The present exclusion of infertility treatment from medical insurance policies reinforces the difficulty in obtaining access to ART for those from less affluent backgrounds. ART remains prohibitively expensive for a large number of infertile people and in the absence of intervention may become or remain the domain of the more affluent groups in New Zealand society.

CONCLUSION

It is clear from the preceding discussion that discrimination with respect to the provision of fertility services and facilities on any of the grounds covered by section 21 of the Human Rights Act is prohibited. The Commission is charged with the investigation of individual complaints of unlawful discrimination under Part lll of the Act. As discussed in the introduction to this submission, the Commission also has roles and functions under Part I of the Act which, include inter alia, inquiring into and acting on matters affecting human rights in New Zealand. Certain situations may require the Commission to find a balance between the rights to nondiscriminatory treatment and other competing human rights.

Few rights are unconditional. It is unsurprising in such a complex and controversial area as ART, that specific rights may be in conflict; that individual rights to equal treatment may compete with wider collective rights and interests, or that the individual rights of different parties are incompatible. In order to effect a fair and equitable balance between these conflicting rights, it is necessary to examine what rights, freedoms and interests are at stake. Fundamental to much of the controversy surrounding ART are perceived conflicts between the rights of the child and the right to found a family.

The rights of the child, while codified in the International Convention on the Rights of the Child, tend to be articulated in vague subjective terms, particularly when reference is made to the child's best interests or welfare. Often appeal is made to the principle of the child's best interest in order to deny fertility treatment to people who do not meet conventional standards of what ideal parents should be like. The submissions received by the Commission on this issue indicate there is little consensus in the community about what constitutes the optimum environment for raising children. Where social consensus cannot be achieved, measures to promote compromise are suggested, for example a widely representative national ethics committee might be able to assess novel or controversial cases.

Reference has been made above to broad judicial conceptions about suitable environments for children. Emphasis is given in the Family Court to the quality of the relationship between child and care giver and quality of the physical and emotional environment proposed for the child. Little or no weight is given to

consideration of a parent's sexual orientation, marital or disability status, and so forth, except where these factors are directly relevant. Guidelines which purport to promote the welfare of children should not reflect societal prejudice and should apply liberal interpretations to consideration of children's welfare in line with contemporary New Zealand jurisprudence.

Under the Human Rights Act anti-discrimination measures have been put in place to protect the interests of minority groups who suffer discrimination in areas of public life. Discrimination may be defined as the unjustifiable, unreasonable or irrelevant imposition of differentiation between people. While the Commission obviously has a concern that any guidelines for access to ART comply with the Human Rights Act and with international human rights standards, the Commission is also anxious to ensure as far as possible that the guidelines do not impose unjustifiable, irrelevant or unreasonable requirements on those seeking access to ART

APPENDIX

SUBMISSIONS MADE TO THE HUMAN RIGHTS COMMISSION REGARDING ACCESS TO ASSISTED REPRODUCTIVE TECHNOLOGIES

Anglican Diocese of Auckland
Anonymous, Auckland
Armstrong, Sarah, Christchurch Patient Advocate Service
Auckland Infertility Society
Benny, Peter, Christchurch School of Medicine
Catholic Archdiocese of Wellington, Office of the Vicar for Education
Catholic Archdiocese of Wellington, Office for Justice, Peace and Development
Catholic Archdiocese of Wellington, Pastoral Office
Christian Fellowship, Upper Hutt
Federation of Women's Health Councils, Aotearoa - New Zealand
Greer, Michael, Rev. District Superintendent, Auckland Methodist District
IHC National Office
Joint Methodist-Presbyterian Public Questions Committee
National Council of Women of New Zealand
New Zealand Aids Foundation
New Zealand CCS
New Zealand Federation of University Women, North Shore Branch
Office of the Privacy Commissioner
Reriti-Crofts, Aroha, past national President, Maori Women's Welfare League
Rishworth, P and Huscroft, G, Law Faculty, University of Auckland
Royal New Zealand Foundation for the Blind
Standards & Monitoring Services
Women's Health Action

HUMAN RIGHTS COMMISSION SUPPLEMENTARY CORRESPONDENCE

The Human Rights Commission's submission to the Ministerial Committee on Assisted Reproductive Technologies did not discuss the implications of Section 97 on the law prohibiting unlawful discrimination. In light of the current media debate regarding access to ART we thought it important that this section be brought to your attention.

Section 97 provides the Complaints Review Tribunal with power to declare that any act, omission, practice, requirement, or condition that would otherwise be unlawful is not unlawful because it constitutes a genuine justification. The application for such a declaration may be made by the Proceedings Commissioner and/or the person against whom the complaint has been made or the person to whom the investigation relates.

In the context of access to ART, if a case arose in which an ART provider felt it would be unreasonable to supply their services to a particular client, the provider could, under Section 97, apply for a declaration that their non-compliance was not unlawful.

The Commission itself is not able to discriminate against persons seeking access to ART. If someone has been refused access to ART on one of the prohibited grounds of discrimination, the Commission is bound to accept a complaint from that person. There may be cases where the Commission or individual officers at the Commission felt that the complainant should not be provided with ART and the discrimination complained of was genuinely justified. In these circumstances the Commission, through an application initiated by the Proceedings Commissioner, could apply for the genuine justification to avoid prosecuting the complaint.

As a matter of policy, the current position of the Commission with regards to Section 97 and access to ART is that the Commission does not plan to initiate any Section 97 application. That is, the Commission will not generally decide when particular complainants' circumstances are such that they should not be provided with ART and discrimination is therefore justified. It will be up to the providers of ART to initiate such applications, although the Commission will need to decide on a case by case basis whether or not to defend any such applications.

Section 97 can perhaps be seen as a safety net provision to avoid unreasonableness that may be caused by the application of the Human Rights Act without exception. It therefore has considerable importance in terms of the legislative framework surrounding ART, particularly while no other law determines rights of access to ART.

A problem with Section 97 is that it will deal with individual cases rather than categories of cases and will provide genuine justification for discrimination only with regard to a particular complaint. Jurisprudence will of course develop guiding parties on the likely success or otherwise of proposed Section 97 applications but it may be that numerous applications will have to be made in the absence of other statutory regulation of access to ART.

It should be added that to date, no applications under Section 97 have been made to the Tribunal in respect of any matter.

GLOSSARY OF TERMS

ART	Assisted Reproductive Technologies
Cervix	The end point of the uterus where it protrudes into the vagina
Coitus	Referring to sexual intercourse
Corpus Luteum	A gland which forms in the ovary following the rupture of the follicle during ovulation and which produces the hormone progesterone in the second half of the normal menstrual cycle
Embryo	The product of fertilisation of egg by a sperm usually referring to the organism after implanting into the uterus but commonly used in IVF to mean the early products of conception.
Endometriosis	The presence of endometrial tissue in abdominal locations such as the fallopian tubes, ovaries and peritoneal cavity
Fallopian tubes	Muscular tubes connecting the ovaries with the uterus
Follicle	The cells surrounding a mature ovum in the ovary
Gamete	Sex cells eg sperm or egg
ICSI	Intracytoplasmic sperm injection
IMCART	Interdepartmental Monitoring Committee on Assisted Reproductive Technologies
Immunology	Relating to the immune system
In vitro	In glass or a process carried out in a culture dish or test tube
In vivo	In a living organism
INECART	Interim National Ethics Committee on Assisted Reproductive Technologies

Laparoscopy	A surgical investigation utilising a telescopic instrument (a laproscope) to view the pelvic organs
Laparotomy	Surgical incision into the abdominal cavity to examine the internal organs
Luteal phase deficiency	Failure of the corpus luteum
Menopause	The physiological cessation of menstruation
NACHDSE	National Advisory Committee on Health and Disability Service Ethics
NECART	National Ethics Committee on Assisted Reproductive Technologies
Oocyte	An immature ova, egg
Ova	Plural of ovum, an egg
Ovaries	Female glands within the pelvic cavity which produce the hormones oestrogen and progesterone and in which the ova are developed
Ovulation	Release of a mature ovum from the ovary into the fallopian tube
Pelvic inflammatory disease	A complication of genital infections by single or mixed pathogens including chlamydia trachomatis which may result in inflammation and occulsion of the fallopian tubes
Royal College RNZCOG	Royal New Zealand College of Obstetricians and Gynaecologists
RTAC	Reproductive Technologies Accreditation Committee
Semen	The fluid containing sperm and seminal secretions which is ejaculated during intercourse or masturbation
Sperm	The mature male gamete
Surrogacy	The bearing of a child with the intention that the child will be raised by others

Testicular biopsy	The process by which a piece of tissue is obtained from the testes
Tubal ligation	An operation in women for surgical sterilisation - by dividing and tying the Fallopian tubes
Testosterone	Male sex hormone produced in the testes
USCACA	Uniform Status of Children of Assisted Conception Act (United States)
Uterus	A pear shaped, muscular cavity lined with endometrial tissue which can expand to make space for a growing foetus. The uterus connects with the fallopian tubes at the top and with the cervix at the base
Vasectomy	An operation in men for surgical sterilisation by dividing and tying the duct along which sperm are transported
Zygote	Fertilised ovum before further division